

A PHOTOVOICE EXPLORATION AND INTERPRETIVE PHENOMENOLOGICAL
ANALYSIS OF CHILDHOOD CANCER SURVIVORSHIP INTO ADULTHOOD

A DISSERTATION
SUBMITTED TO THE GRADUATE SCHOOL
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE
DOCTOR OF PHILOSOPHY

BY
ERIN LEIGH SADLER

DISSERTATION ADVISOR: DR. DONALD R. NICHOLAS

BALL STATE UNIVERSITY

MUNCIE, IN

DECEMBER 2016

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Dedication

Sarah Marie Gould (1984-2002)

Seth Ivan Caine (1985-2014)

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“I can no other answer make, but, thanks, and thanks.”

-William Shakespeare

Over the course of writing this dissertation I have encountered many joys and equally as many growing pains. In the beginning of this process, I had little to no self-efficacy in conducting individual, original research. With so many ideas in my mind, I had difficulty narrowing this project down to something remarkable, yet achievable. With the support of a number of people I was able to develop this project into something I love and am proud of. All of the challenges and hurdles of completing this project have led to tremendous learning and growth and, resultantly, I have also developed a deep and profound appreciation for the people who supported me along this path. Without these professional and personal relationships, I would not have found the courage and sustained the effort to see this project to the end.

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Abstract

This study explored adult childhood cancer survivors' experiences with illness and survival. Currently, there is an abundance of medical and physiological research regarding childhood cancer survival into adulthood, including the physical late effects of the disease treatment. There is, however, a limited understanding of if and how childhood cancer survivors make meaning of their illness and how this contributes to their psychosocial functioning, including posttraumatic stress and/or posttraumatic growth. Using a qualitative technique known as photovoice, participants of this study described their experiences with illness and survival via visual story telling. A total of 8 (7 females, 1 male) adult survivors of childhood cancer completed the photovoice protocol and a team of researchers engaged in an interpretive phenomenological analysis of the verbal and visual data. Three themes with accompanying subthemes were identified and include biopsychosocial stressors, meaning-making, and posttraumatic growth. The interactions of these themes revealed that childhood cancer survivorship into adulthood is anything but a linear model of recovery after biological cure of the disease. Specifically, the participants' reported continuous biopsychosocial stressors from the onset of the illness, including a cyclical meaning-making process that contributes to these stressors. Each participant, however, also experienced a degree of posttraumatic growth. A developmental, contextual model for the experience of childhood cancer survivorship into adulthood is proposed. Clinical implications for how healthcare professionals could theorize and understand the development and transition of childhood cancer patients into adulthood, as well as future research directions are discussed.

Keywords: Childhood cancer, survivorship, photovoice, interpretive phenomenological analysis, posttraumatic stress, posttraumatic growth

A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood

Childhood cancer survivorship into adulthood is a profound biopsychosocial experience that has long been viewed from the lens of traditional biomedical models of disease. While close attention needs to be paid to disease treatment and physiological late effects of treatment, in order to fully understand this unique life experience, we need to augment the medical model. Biological cure is unquestionably a landmark for the individual and the family; however, the full psychosocial meaning and experience of survival is relatively unclear. As the childhood cancer survivor grows into adulthood, the chronic nature of the physiological late effects including an increased risk for developing a second malignancy (Meadows, 1991), cognitive impairment (Anderson, Rennie, Ziegler, Neglia, Robinson, & Gurney, 2001; Butler, Hill, Steinherz, Meyers, & Finlay, 1994; Eiser 1991; Meadows et al., 1981), and infertility (Byrne, et al., 1987; Green et al., 2009) become threatening (Brougham, Kelnar, Wallace, 2002; Meadows, Gallagher, & Brunin, 1992). Further, the literature has focused on deficits in coping and adjustment (Eiser, 1994; Parry & Chesler, 2005; Walsh, 2006) and there is consistent evidence for psychological difficulties for a significant percentage of survivors (Hobbie et al., 2000; Langeveld, Grootenhuys, Voutes, & deHaan, & Bos, 2004; Rourke, Hobbie, Schwartz, & Kazak, 2007; Recklitis, Diller, Li, Najita, Robison, and Zeltzer, 2010; Zebrak et al., 2002; Zeltzer et al., 1997, 2009).

In recent years, the survivorship literature has evolved and refocused to include the study of personal growth. Specifically, some studies suggest the traditional deficit oriented approach to life threatening illnesses, such as childhood cancer, overlook the positive psychological changes and transformations such as growth, wisdom, self-knowledge and awareness, and the

purpose and meaning of life (Ickovics & Park, 1998; McMillen, 1999; Paterson, Thorne, Crawford, & Tarko, 1999; Siegel & Schrimshaw, 2000; Tedeschi & Calhoun, 1995; Walsh, 1995, 2006; Wolin & Wolin, 1993). A plethora of empirical data indicates long-term survivors of childhood cancer experience normal levels of psychosocial adjustment and potential personal growth (Cella, et al., 1987; Fritz, Williams, & Amylon, 1988; Fritzs & Williams, 1988; Greenberg et al., 1989; Spirito et al., 1990; Tebbi & Mallon, 1987). Parry and Chesler (2005) noted that psychosocial concerns are common among adult survivors of childhood cancer, even among those survivors who experience personal growth. While the existing literature has divided psychological difficulties and personal growth into two separate experiences, it is important to understand that subjective pain and growth might coexist due to the process of making meaning of a traumatic event like childhood cancer diagnoses and treatment (Yalom & Lieberman, 1991).

Meaning-making has a long history in the psychological health literature since the publication of Frankl's (1963) account and observations during his imprisonment in Nazi death camps. Throughout history, many thoughtful psychologists including Fromm (1947), Frankl (1961), and Yalom (1980) have written about the possibilities of positive effects and change that occurs as a result of stressful life events, like a childhood cancer diagnosis and treatment. Multiple studies have reported that meaning-making processes and the attempts that result in meaning made are correlated with better adjustment, including cancer survivorship (Bower, Kemeny, Taylor, & Fahey, 1998; Fife, 1995; Lee, Cohen, Edgar, Laizner, & Gagnon, 2006; Park, Malone, Suresh, Bliss, & Rosen, 2008; Tolstikova, Fleming, & Chartier, 2005; Westling, Garcia, & Mann, 2007). However, it is also noted that while the *presence* of meaning is adaptive, the

search for meaning is linked with experiences of increased distress and more negative changes (Linley & Joseph, 2011).

The existing research indicates the search for meaning is associated with more symptoms of depression and higher reports of neuroticism (Steger, Frazier, Oishi, & Kaler, 2004; Steger, Kashdan, Sullivan, & Lorentz, 2008). Joseph and Linley (2005, 2008) built on the writings of Yalom (1980) and Janoff-Bulman (1992) and stated that traumatic events shatter a person's assumptions about the self and the world, which propels that person to search for new meanings in life. The authors further stated that as meaning is created or found the person reconstructs their worldview and new assumptions unfold. Overall, the process of meaning-making can be considered vital for creating positive change in adjusting to a stressful life event, despite the challenges the search for meaning requires.

As this area of psychological literature continues to evolve it is important to recognize the most notable omission in the research on childhood cancer survivorship into adulthood: a developmental perspective of the entire diagnosis—treatment—survival process. A more complex, contextual model is necessary for understanding both the difficulties and the personal growth experienced by this population. At this stage of understanding childhood cancer survivorship into adulthood, the challenge is to clarify the functional significance of meaning-making in their biopsychosocial experiences with the illness. To gain a holistic understanding, qualitative methodologies were used in this study to assess difficulties and meaning-making from the perspective of the survivor within his or her biopsychosocial context. Specifically, the use of the participatory action research approach, in which the participants actively collaborate with the researchers throughout the process, enabled survivors to communicate the biopsychosocial meanings of childhood cancer survivorship.

Further, participatory action research provides an avenue for social and healthcare changes to occur and enhance the understanding of childhood cancer survivors' needs and experiences. Additionally, the existing *empirical* literature has not matched the depth, richness and complexity of that described in the existential and trauma *theoretical* literature in their explanations of meaning and meaning-making. The abstract and metaphoric nature of these constructs (meaning-making and posttraumatic growth) call for more creative methodologies to capture the breadth and depth of their complexities (Park, 2010). When discussing such complex concepts, words alone can be insufficient in communicating a comprehensive understanding (Brunsden & Goatcher, 2007). Visual imagery offers an alternative route to articulate complex experiences and emotions that language cannot, in and of itself, convey (Brunsden, Goatcher, & Hill, 2009). (For a more thorough review of the literature see Appendix A.)

Using Photographs as Research Data

Since its inception, the photograph has never gone out of style. Largely because photographs allow us to gaze at people and experiences that seem very familiar to us and, yet, almost unimaginably different, at the same time. We feel our connection and our distance in equal measure. Sontag (1977) described a photographer as the following:

An acute but non-interfering observer - a scribe, not a poet. But as people quickly discovered that nobody takes the same picture of the same thing, the supposition that cameras furnish an impersonal, objective image yielded to the fact that photographs are evidences not only of what's there, but of what an individual sees, not just a record but an evaluation of the world. (p. 88).

Sontag's idea of how the photographer objectively documents his or her individual evaluation of the world provides a framework for utilizing photographs as data. With the ability to transmit multiple messages, pose questions, and point to both abstract and concrete thoughts of participants, photographs elicit emotional and intellectual responses (Weber, 2008) and seize "the

fullness of lived experiences by describing, interpreting, creating, reconstructing, and revealing meaning” (Watrin, 1999, p. 93). Resultantly, photographs have been used as data in anthropological and psychological research (Collier & Collier, 1986; Combs & Ziller, 1977; Dinklage & Ziller, 1989; Ziller & Rorer, 1985). Photographic data has the power to provide access into the participants’ lives that shapes our understanding and potentially develops shared meaning that is otherwise inaccessible via self-reports and fact descriptions (Eisner 1997).

Barthes (1981) notes the photograph has two levels of meaning: denotative and connotative. The denotative meaning is the literal meaning, or the objective reality the photograph documents. The connotative meaning refers to the cultural and historical context of the image including social conventions and contextual codes. Taking into consideration these two levels of meaning, photographs can provide rich data that includes creating metaphors to form ideas and explanations for difficult to articulate experiences. There are, however, some limitations to using photographic data. While photographs can provide rich, detailed perspectives, they also incorporate the risk of imprecision (Eisner, 1997). Specifically, anyone can ascribe meaning to photographs, they are forms of art after all. To meet the complex needs of developing a more comprehensive understanding of childhood cancer survivorship into adulthood in a way that provides a depth and richness to illustrate this profound experience, as well as obtaining the most reliable and valid data, this study required more than one qualitative analysis. Qualitative researchers utilize a wide array of methods in order to gain a deeper understanding of the subject matter they are exploring and each qualitative method makes the world visible in a different way. Therefore, there is “frequently a commitment to using more than one interpretive practice in any study” (Denzin & Lincoln, 2004, p. 3-4). This study blended

the participatory action research method of photovoice with interpretive phenomenological analysis (IPA).

Photovoice & Interpretive Phenomenological Analysis.

The photovoice methodology involves giving cameras to participants with the intention of using photography to identify, represent, and enhance their communities (Wang & Burris, 1997). This methodology has been growing in popularity and has been used to gain a better understanding of the experiences of homeless people (Radley, Hodgetts, & Cullen, 2005), senior citizens (LeClerc, Wells, Craig, & Wilson, 2002), rural Chinese women (Wang & Burris, 1997), immigrants (Streng, et al., 2004) mothers with learning disabilities (Booth & Booth, 2003), refugee youths (Berman, Ford-Bilboe, Moutrey, & Cekic, 2001), foster carers (Pickin, Brunsden, & Hill, 2011), and people living with HIV/AIDS (Hergenrather, Rhodes, & Clark, 2006). The primary goals of photovoice are to (a) enable participants to document and reflect on their community's strengths and concerns through photography, (b) promote critical dialogue and knowledge about important issues through discussion of participants' photographs, and (c) reach policy and decision makers through public forums and exhibitions of their photographs (Wang, 1999; Wang & Burris, 1994). As photovoice was originally devised and utilized in sociological and public health research, there is a need to reconfigure it to meet the needs of psychological research (Brunsden & Goatcher, 2007). Specifically, a more detailed, analytic process is required. Brunsden and Goatcher (2007) suggest using interpretive phenomenological analysis (IPA) to supplement the coding done by the participants in the photovoice project.

IPA is distinct from other forms of qualitative research in that it uses a combination of psychological, idiographic, and interpretive components to explore how participants are making sense of their personal and social world and involves a detailed examination of their life, world,

personal experiences, and personal perceptions about an event (Smith & Osborn, 2008). IPA was first established in the area of health psychology (Brocki & Wearden, 2006) and is widely used in psychological research in Britain (Duncan, Hart, Scoular, & Brigg, 2001, Thompson, Kent, & Smith, 2002; Clare, 2003; Biggerstaff, 2003; French, Maissi, Marteau, 2005). IPA has been used to explore the experiences of palliative care patients (Muggleton, Guy, & Howard, 2014), adolescents with haematological malignancy (Al Omari & Wynaden, 2014), spinal cord injury patients (Nunnerley, Hay-Smith, & Dean, 2013), patients with lower extremity ulcers (Wellborn & Moceri, 2014), patients with osteoarthritis (Bukhave, la Cour, & Huniche, 2014), women with gestational diabetes (Carolan, 2013), and compulsive hoarding (Kellet, Greenhalgh, Beail, & Ridgway, 2010).

Both photovoice and IPA are rooted in hermeneutics and phenomenology, therefore, IPA adds a layer of understanding regarding developmental and cumulative effects the individual experiences in childhood cancer survivorship. The use of IPA allowed us to explore *how* adult survivors of childhood cancer ascribe meaning to their experiences in their interactions with the environment (Smith, Osborn, & Jarman, 1999). Blending photovoice with IPA has the potential to provide a richer interpretation of one's experience; a developmental perspective of the entire diagnosis—treatment—survival process of being an adult survivor of childhood cancer. (For a more thorough review of the literature see Appendix A.)

The purpose of this study is to explore the experiences of adult survivors of childhood cancer with making meaning of his or her illness and to propose a developmental perspective of the entire diagnosis—treatment—survival process. Further, this research intends to make salient the importance of promoting the best long term possibilities for adult survivors of childhood cancer. Childhood cancer survivorship into adult is a complex, biopsychosocial experience and

includes constructing meaning of the illness. The meaning-making literature calls for more creative measures of such an abstract concept (Park, 2010) and, therefore, creative forms of data may prove to be more effective in eliciting reflections about these experiences than standardized, self-report questionnaires. This study utilizes photographs to allow meanings to form in different ways and provide the opportunity to go beyond the limitations of the self-report measures that hinder meaning-making research (Park, 2010) and to make connections between research and lived experience (Garoian, 1999).

Method

Participants

Initial sampling of participants was conducted using criterion sampling, a form of purposive sampling in which participants are selected because they meet an important predetermined criterion (Polkinghorne, 2005). In this study, the primary criterion included: (a) diagnosis of cancer between the ages of 0-17 and (b) having been off treatment for at least three years. Further, a snowball procedure was used via email and social networking sites (e.g., Facebook) to disseminate the study and recruit participants. (see Appendices B & C).

A total of eight participants completed the study protocol. While twelve participants were recruited, there was significant attrition. This attrition was attributed to the time-consuming nature of the protocol, as well as some reported anxiety of discussing the personal narrative of survivorship. All of the participants who ended their participation did so between the first meeting and the second meeting. In order to protect the participants' confidentiality, each was assigned a pseudonym (see Table 1). Participants were both male and female survivors of childhood cancers; however, the majority were women ($n = 7$). All of the participants identified as Caucasian. The ages of the participants fell between 18-34 years and with the mean age of

25.75. Age at diagnoses ranged from 10-15 and time since diagnoses ranged from 3 to 23 years.

Treatment modalities varied and included chemotherapy, radiation, and surgical resection.

Diagnoses included acute lymphoblastic leukemia (n = 2), Hodgkin's lymphoma (n=1) Wilm's tumor, or nephroblastoma, (n = 1), rhabdomyosarcoma (n = 1), Dermatofibrosarcoma protuberans (n = 1), osteosarcoma (n = 1), Ewing's sarcoma (n = 1).

Table 1.

Demographic and Data Information by Participant

Participant Pseudonym	Age	Gender	Marital Status	Age & Diagnosis	Education	Interview Duration	Number of Photos
Jasmine	28	Female	Married	10 Nephroblastoma	BA	2 hours 30 minutes	27
Sam Talon	18	Female	Single	14 Hodgkin's Lymphoma	BA in progress	1 hour 38 minutes	15
Elphaba	18	Female	Single	15 Dermatofibrosarcoma	BA in progress	1 hour 28 minutes	7
Alicia	28	Female	Married	11 A.L.L.	M.D.	2 hours 18 minutes	22
Edward	22	Male	Single	15 Osteosarcoma	BA in progress	1 hour 24 minutes	4
Orion	32	Female	Married	13 A.L.L.	MA	1 hour 34 minutes	5
Molly	35	Female	Single	8 Ewing's sarcoma	BA	1 hour 29 minutes	9
Alice	29	Female	Single	6 Rhabdomyosarcoma	BA	2 hours 28 minutes	11

Procedure

Photovoice Training. This initial interview gathered basic demographic data to determine eligibility for the study. Further, this meeting provided a general overview of the photovoice process and to train the participants in photographic techniques. The participants were provided with a project overview letter (see Appendix D) Based on Wang and Burris' (1997) method, this training included a discussion of photography, ethics, and power; ways of seeing photographs; and a philosophy of photography. Technical advice during this training was kept to a minimum as to not stifle the participants' creativity and own personal style, however, the principal investigator provided basic information regarding perspective, lighting, balance, contrast, and other techniques that could help the participants represent their experiences and struggles through their photos. Additionally, a sufficient amount of time was allotted to discuss issues of power they hold as a photographer.

The principal investigator outlined the requirements for the study in this session and the participants signed the informed consent form, media release form, and provided demographic information (see Appendices E, F, and G). Specifically, the researcher discussed the photography prompts (see Appendix H) as being a guide for capturing his or her survivorship experiences. A list of instructions, tips, and outlines for ethical behaviors when taking photographs (see Appendix I) was also distributed. It is noted that participants could expose their identity if they engaged in self-portraits and this was made clear to participants during this first meeting. If participants planned on taking photographs of other people, they were also provided applicable consent and contact information forms (see Appendices J-N). Participants obtained consent from any person they photographed as a part of a study and these identities are kept confidential. Those photographed were offered a personal copy of the consent forms, as well as copies of any

photographs that they appear in. The participants and the researcher agreed on a timeline for project completion and the camera and images were returned to the principal investigator. Once the photographs were received by the researcher the second interview was scheduled.

Data Collection. With permission, the second interview was audiotaped and largely focused on discussing the images the participants produced. The second interview lasted on average of 1 hour and 45 minutes. The purpose of a photograph discussion, according to Wang and Burris (1997), is to enable the participants to reflect on the images that they have produced. Photographs were numbered in the sequence in which they were captured and tagged to the participant and release forms. During the second meeting, the participant engaged in the three-stage process of photovoice (Wang & Burris, 1997). This process includes 1) selecting the photographs; 2) contextualizing, or telling the stories of the photographs; and 3) codifying the photographs—participants code the data provided by their photographs into themes and issues that emerge from the discussion (Wang & Burris, 1997). Each of these stages were completed during this meeting.

Selecting the photographs. Each participant shared a selection of his or her photographs with the principal investigator. There was no minimum or maximum number of photographs each participant selected for discussion. The participants titled and provided captions that told the story for each of the photographs they selected.

Contextualizing the photographs. The principal investigator utilized a semi-structured interview technique and encouraged participants to discuss why their photographs are significant. Participants answered questions such as “How does this photograph represent what it is like to be a survivor of childhood cancer? What are the most challenging parts about being a childhood cancer survivor? What are some things you have learned from your illness?” (see Appendix O).

Codifying the photographs. In this stage, the participants identified themes and issues that were discussed during this meeting as a way to summarize their photographs. Using this approach, the study avoided the distortion of fitting data into a predetermined model. By the end of this session, the participant coded each photograph into at least one theme that the participant created via their discussion. The principal investigator created an electronic file to organize the photographs by title, caption, themes, issues, and theories.

Debriefing and Photo Exhibition Planning. At the end of the second meeting, the principal investigator debriefed the participants and provided information about how the study proceeded. Each participant was provided with \$25 in cash or specified a children's hospital to which \$25 was donated in his or her name. Funding for the project was obtained via the Joseph W. and Marcella S. Hollis Fund. During debriefing, the principal investigator discussed the development of an online exhibition of the participants' images. Participants were reminded this is a voluntary exhibition and they are not required to show their work to the public. All of the participants elected to share their photographs in the public exhibition, which is located online at www.survivorshipstories.wordpress.com. Lastly, the principal investigator asked process and termination questions (see Appendix P).

Data Management and Storage. The audio and photographic data collected were uploaded to a personal, password-protected laptop. All electronic files, including MP3, JPEG, and Word files will be stored indefinitely on this password-protected laptop. The data will be anonymous due to the use of self-assigned pseudonyms. The tangible photographs are stored in a locked filing cabinet in the principal investigator's home office and kept indefinitely. At the end of each photograph discussion, the principal investigator transcribed the digital audio files verbatim to become the "raw data" and inserted notes and reflections (e.g. emotions expressed,

voice inflections, and affect), as well as numbered photographs in the text to correspond with separate digital photo files. The principal investigator checked each transcription for accuracy.

Data Analysis. There are two sources of data: photographs and the interview. The photographs served two purposes in the study: 1) as a source of data, in and of themselves, and 2) to elicit critical awareness of the participant to provide rich, detailed verbal data. The data was organized into visual and verbal categories and coded accordingly. Two master tables were created, one for each set of data. The tables of themes were constructed on not only the frequency of their occurrence in the data, but also on the richness of the passage that highlight the themes (Smith & Osborn, 2007). For a detailed view of the data analysis process, see Appendix R.

Interpretive Phenomenological Analysis. The principal investigator assembled and trained a research team to conduct an interpretive phenomenological analysis to analyze the verbal data as a way to increase reliability/validity. The research team engaged in IPA as a cyclical process and moved through the following stages with the verbal data: 1) First encounter with the text and associated photographs; 2) Preliminary themes identified; 3) Grouping themes together as clusters; and 4) Tabulating themes in a summary table (Smith & Osborn, 2008).

The IPA process began with reading the transcripts a number of times to become as familiar as possible with each participant's individual experiences and using left-hand margin to annotate what he or she finds interesting and/or significant about the participant's response in the interview text. In the second stage, the researcher used the right-hand margin of the interview transcript and to document emerging theme titles (Smith & Osborn, 2008). This process involved transforming the initial notes in to more concise phrases that may include more psychological terminology and transformed the initial impressions and notes into themes.

The third stage included chronologically listing the themes and looking for connections between them. During the fourth stage, the researcher ordered a table of the superordinate themes and subordinate themes. The themes were given names and a table was created as a summary of which superordinate themes go with each subordinate theme. When the researchers completed the IPA for each of the transcripts, the principal investigator conducted an IPA across the team's codes. Specifically, connections were made throughout the themes and a master table was created.

Photovoice. As part of the photovoice procedure, the participants coded their own photographic data, thus, it was not the principal investigator's role to assign meaning to the photographs, but rather organize and consolidate the data across participants. As mentioned previously, the participants titled and captioned their photographs, as well as coded each into a superordinate and subordinate theme. The principal investigator conducted steps 3 and 4 of IPA with the photographs and compiled a master table of the visual data to include superordinate and subordinate themes to match the data provided by the group of participants. Specifically, the principal investigator used their words and codes without forcing them into a predetermined set.

Independent Audit. The final tables, figures, and results were presented to the research team for an audit. The team consulted the original transcripts and their codes for a final appraisal regarding the master tables' accuracy and fidelity. Further, the principal investigator conducted an independent audit, a powerful way to increase validity of qualitative data (Smith. Flowers, Larking, 2012). According to Yin (1989) a qualitative researcher can check the validity of the final research report by filing the data in a way that a person unfamiliar with the procedure and data could follow the "paper trail" of the project. The principal investigator of this study organized both the digital and hard copy data, including initial notes, the research proposal, the

interview schedules, procedures, audio recordings, transcripts, tables, and drafts of the report in a coherent chain of events from the initial project notes to the final report. Specifically, folders and files located on the principal investigators' laptop computer. Further, these files and folders are compiled in a chronological fashion and appropriately organized, titled, and numbered in an order that is easy to follow. It allowed the principal investigator to check the rigor of the claims of this study.

Reflective Journaling. Part of the overall qualitative research methodology includes acknowledging the researcher as being subjective and biased (Chang, 2008; Ellis, 2004). In order to address the inherent biases found in qualitative research, methods such as reflective journaling are employed to provide the researchers with deep understanding of his or her experiences in the study. This will also allow the reader to “assess how and to what extent the researcher’s interests, positions, and assumptions influenced inquiry” (Charmaz, 2006, p. 188). Further, reflective journaling enhances the researchers’ self-awareness during the implementation of the study and “aids in making visible practice and construction of knowledge within research in order to produce more accurate analyses of our research” (Pillow, 2003, p. 178). Researchers wrote a journal entry for every block of coding he or she completed.

Results

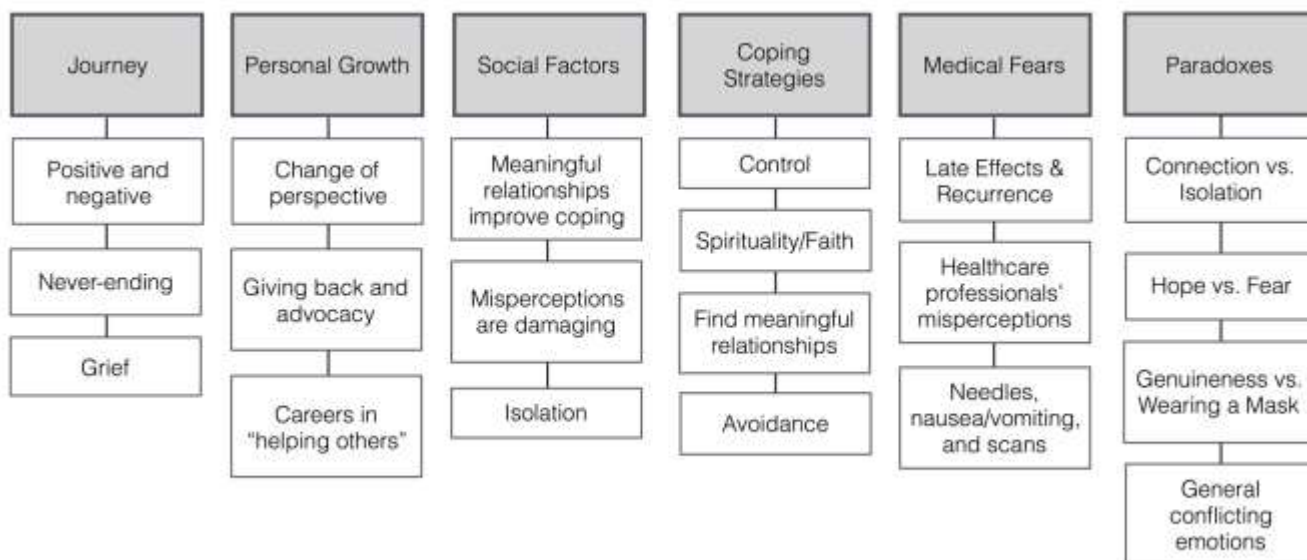
The results will be presented two fold. The first section is based on the participants’ codes from the photovoice portion of the study, as well as the principal investigator’s IPA of the photographs. The second section will provide the detailed interpretations of the research team via IPA. The results of this study are from the very specific stories and experiences generated by eight adults who survived childhood cancer.

Results of Photovoice

The visual data is presented in the words and context of the participants and, therefore, little extrapolation is made to ensure the fidelity of their codes. Using the participants' own words to illustrate themes retains the voice of the participants' personal experience and presents the reader with an emic perspective. Six superordinate themes emerged — 1) survivorship is a journey, 2) personal growth, 3) social factors, 4) coping strategies, 5) medical fears, and 6) paradoxes. Each theme contains a collection of subordinate themes (see Figure 1). The themes are comprised of the participants' exact words and specific codes.

Figure 1.

Structure of Themes and Sub-themes of Photovoice Analysis



Survivorship is a Journey

Positive and Negative. The data revealed the majority of participants' view childhood cancer survivorship as a "journey" that has both positive and negative elements. There is considerable mention of the benefits and struggles survivorship poses. Benefits included a sense of continual personal growth and introspection into how the illness continues to affect their

survivorship. Struggles included coming to terms with a lack of control over one's life and becoming comfortable with ambiguity. As one participant explained,

There are bad days, much like stormy days in seasons, and then there are days that seem a bit better, and you feel a bit more hopeful that the storm will pass. And then there are great days, where you finally made it through the storm and the sun is shining. And it all seems to repeat itself.

Never-ending. The participants also described survivorship as a journey that “never ends”. This never ending journey is marked with continuous reminders of their illness in the forms of late effects and threats of recurrence. Each participant that discussed survivorship as a journey noted the ebb and flow of this experience and they anticipate this will be a permanent part of their existence. The phenomenon was best expressed by one participant's photograph and caption (see Figure 2).

Figure 2.

The Dark and Light Sides of the Crack



Caption: This represents that the journey is never-ending and you move between lightness and darkness. I want to feel like I am on the other light side of the redline. The

redline is the cancer diagnosis. I do the best I can to stay on the light side. Childhood cancer follows you, though, and it never ends with cure. It is a lifelong journey.

Grief. All of the participants noted a feeling as if they “lost their childhood” and, therefore, experienced a grieving process for that loss. As a result, these childhood cancer survivors experience a sense of loss of an entire developmental experience. This is compounded as a majority of the participants also noted the death of a fellow childhood cancer patient in their youth and fellow childhood cancer survivor in their adulthood. A representation of this experience is found in the comment of this survivor:

It’s just a big feeling of sadness, that childhood cancer robs so many people of the opportunity to grow up, and the ones that are fortunate enough to make it, it still robs them of their childhood, and a lot of experiences that other kids get, because you’re forced to grow up so much quicker than other people, and you miss out on a lot of being a kid. You grieve so much loss at such a young age.

Personal Growth

Change of perspective. The most frequent and palpable response to how this group of childhood cancer survivors described their post cancer life was a notable “change in perspective”. All of the participants discussed and photographed a multitude of positive psychosocial experiences as a part of survivorship. Specifically, all of the participants noted an increase in each of the following traits: empathy, gratitude, optimism, hopefulness, flexibility, mental strength, and appreciation for beauty. One participant, a medical doctor beginning a specialization in pediatric hematology/oncology, provided this evocative statement,

I wish people could gain the perspective on life that I have gained without going through the torture of cancer. When diagnosed with cancer, I felt like a blindfold had been lifted from my eyes. I wake up each day and realized what a gift it is to be alive and to be able to do the things I do.

Another survivor, a college student, expanded on the above with her comment,

There is a brighter side in all of this dark stuff and feeling like a better person. So that perspective is always around now. The perspective that life is a battle but it is worth it to fight for. I think the perspective that I have makes my life more meaningful and that my cancer had a purpose to give me this perspective.

One survivor provided a photograph in regard to her personal growth and changed perspective on her existence, see figure 3,

Figure 3.

Just Living is Not Enough



Caption: There is a transformation, kind of relating to metamorphosis. And I won't ever know what I would have been had I not had cancer. Who I would have been, what would have happened. You've got to embrace what you are next because that's just what happens. I worked through things so I don't feel quite so guilty anymore about surviving. It doesn't have the hold on me that it once did.

In addition to a change in perspective, a majority of these childhood cancer survivors noted an increase in empathy for others and a decrease in judgmental thoughts and behaviors. A 28-year-old female survivor noted

I just have so much love for people and I care so much about them. I try to understand and empathize more with them after being diagnosed. Because I have endured so much suffering I am more likely to empathize and support others in their struggles.

Regarding flexibility, a 22-year-old male survivor provided this passage,

Before I had cancer I had big dreams to be an Army Officer and even though cancer stole that dream from me, I found way to grow from the experience and be more flexible when unexpected things happen in my life.

Another survivor speaks about the mental fortitude she gained as a result of her cancer treatments,

I guess I draw a lot of strength from my experiences, because all I have to do is remember what I went through and how hard it was to overcome some things, but I overcame them and I know I can overcome a lot as result. There is a lot of life's lessons in this experience.

An additional response in this theme of participants' photographs is the experience of cultivating gratitude. Each of these survivors provided emphasis on how cultivating gratitude has provided them with a level of personal growth they believe would not have been obtained without their experience of being an adult survivor of childhood cancer. This experience is conveyed by a photograph captured in Figure 4.

Figure 4.

Thankful



Caption: At the end of the day, no matter how hard this is or how tough it is, I look out at the beautiful world, and I'm just so thankful to be alive, and to be able to be here to experience it. All the good and all the bad. I'd do it all over again if I had to, because it

made me who I am today. It's still an uphill climb every day and there's a lot of bumps along the way, but at the end it I get to look down and see beauty all around me and that is what gets me through.

Giving back and advocacy. All of the participants discussed “giving back” and being an advocate for the advancement of more targeted childhood cancer treatments, as well as developing an awareness for the survivorship experience into adulthood. One participant, a woman with two young children and a Master's of Divinity, described her experiences in the following passage,

So much about being a childhood cancer survivor is invisible. People can't see it and, therefore, they can't understand it. It is kind of my mission to start making the invisible, visible. So I'm an advocate for making these experiences known and it is very healing to me.

Another survivor noted advocating for more targeted treatments,

I realize how fortunate I am to have survived. I wish all others who face childhood cancer are able to survive. This pushes me to increase awareness of childhood cancer and continue to advocate for better treatments, so that more have the opportunities in life that I do. I also advocate for more target therapies. Safer therapies, that aren't as toxic, to reduce symptoms that survivors experience.

Careers in “helping others”. A majority of the participants either were preparing for or are established in careers of a helping profession. The sample included a medical doctor beginning a specialization in pediatric oncology, an oncology nurse, pastoral counselor, a social work major, a licensed social worker, and psychology major. Each of these survivors described why they chose a helping field and noted these career avenues as a way to use their experience with illness to make a positive impact on the world. One woman expressed the following about her career,

I wake up every morning excited to go to work and it just feels really, really, really good to use such a negative experience to positively impact people.

Social Factors

Meaningful relationships improve coping. This group of adult survivors of childhood cancer discussed the importance of finding and developing meaningful relationships. The majority of the participants indicated how vital these relationships are to their psychosocial functioning. One participant stated the following about how a meaningful relationship helps her cope with survivorship,

She listens to me and I don't have to filter my words or shield anything from her. I hate being vulnerable, but I am able to be vulnerable with her because she just listens and doesn't tell me to "be positive" or "at least you are alive". It helps me feel normal and that I'm not crazy for feeling bad about having cancer or being scared of late effects. There was special attention paid throughout the coding sessions to the importance of

making meaningful connections with other adult survivors of childhood cancers. Three of the participants asked the principal investigator during the initial meetings if she had difficulties in finding survivors willing to discuss their experiences. One participant specifically noted,

I don't know if you have noticed, but not a lot of adult survivors of childhood cancers want to talk about their experiences with someone who is not a survivor of childhood cancer.

When explaining the general childhood cancer survivor community, one participant provided the following insight,

It's just a such a special bond when you meet another childhood cancer survivor. It's unspoken. I've worked really hard to build connections with other survivors because that's who gets me through. I think that is so important as a survivor. No one else gets it and we hear a lot of "just stay strong" and "be positive" from people who aren't survivors and we don't want to hear that. So we tend to not talk about it with people who aren't survivors like us.

Misperceptions are damaging. As noted above, these adult survivors of childhood cancer expressed specific fears in regard to how others perceive their experiences, therefore, this was a prevalent topic of conversation. Participants indicated a culture in which people label adult survivors of childhood cancer as "abnormal" in that they are "braver, stronger, and always

positive”. All of the participants disagreed with these labels and stated, with strong conviction, that they are “just normal people with normal emotions” and “no braver than the next person.”

One participant emphasized this experience in a moving passage in hopes it would change some of these misperceptions,

We are human like everyone else, and as human beings we experience the same range of emotions as normal people. We aren't stronger than anyone else. We aren't braver. We are just people who for some reason, experienced a terrible, terrible disease. We suffered, we endured, but it was not a special power. I bleed when I am cut, and I hurt when I am sad. And when you don't allow us to experience these emotions by telling us to “just be positive” or “just be strong,” it just suppresses our psychological healing from this life's injuries and makes us feel abnormal and unjustified to have our true feelings.

Each participant who expressed concerns about misperceptions also noted the psychosocial distress caused by them. They noted how these misperceptions and comments lacking in empathy and understanding contribute to an overarching feeling of social and existential isolation.

Isolation. The theme of isolation arose out of how misperceptions of others can cause psychosocial distress. Isolation was noted as being a major facet of childhood cancer survivorship into adulthood. The participants indicated feeling alone and practiced isolating themselves from others. Each participant noted how isolation is an integral, albeit negative, part of childhood cancer survivorship and is due to the misperceptions and schemas that family, friends, and the culture places upon them. A depiction of this isolation was provided by one of the survivors and is seen in Figure 5.

Figure 5.

The Last Friend

Caption: I always wonder if others feel as alone as I did, as I still do. I felt alone then, because no one really got it. I feel alone now in that people don't get what the after effects of childhood cancer are like. There is always a state of isolation, of loneliness based on where you are at in your treatment or survivorship, and that feeling never really goes away.

Coping Strategies

Control. A majority of the participants discussed feeling their life circumstances are as “not in my control” so they began to cope via finding things they could control, including diet, exercise, education, being mindful, and self-care activities. Many participants indicated their sense of control allows them to feel as they can reduce their health risks in the future, including reducing the risk of recurrence. One survivor provided a photograph to described how she used control to cope with treatment and survivorship, see Figure 6.

Figure 6.

Ups and Downs

Caption: I knew I was going for treatment I would have to keep still and be strapped to a table with a mask on my face, I made sure I enjoyed every second walking down the stairs until I got there. I controlled those moments walking down the stairs, making myself think of coming out on the other side and that kept me going. I still do this today, try to make myself look at the ups, when everything seems to be down. Somehow this control makes things more predictable and it is easier to cope if I can predict.

Another participant noted how her control is largely focused on diet and exercise,

Diet and exercise is a part of my coping. I have a bad association with it because I know I need it. Like I feel like I could die if I don't keep myself healthy and exercise regularly. I do everything I can to try to make my cancer never comeback. I hate it, but I do it so I can control what I can control.

Spirituality/Faith. Half of the participants noted using spirituality and faith as a way to cope with the struggles of survivorship. Many expressed a new or strengthened spirituality and faith. Most of those who noted their faith indicated it provides them with a sense of relief from

the isolation they feel among their peers. A participant shared her experience with how her spirituality changed after her childhood cancer diagnosis in the following passage,

I never really believed and never prayed or anything and then I got cancer and I was like “Oh great, now I can’t be religious and get close to God because I am dying and that’s no way to come to God now.” But I went to church a couple of times and a lot of church groups approached me and helped me out. Now I know that I am never alone, because I have faith.

Finding meaningful relationships. This group of childhood cancer survivors expressed the importance of meaningful relationships in recovery and survivorship. Each participant expressed the ways in which their close relationships with others help them cope. The following is a statement of one participant expressing what makes relationships meaningful and healing,

I think knowing that someone will be there unconditionally, no matter what comes your way is what makes it ones of those meaningful, healing relationships. Also knowing that the person won’t judge you for feeling the way that you feel. I think a meaningful relationship is one where you know the person is there for you unconditionally and someone with who you can be who you really are. And you know that they will be there to encourage you and support you. Or just simply give you a hug when you need one and doesn’t say “stay positive.”

Avoidance. Half of the survivors noted in their coding of the photographs a behavioral pattern of avoiding visits to their current physicians and healthcare providers. They specified this avoidance occurs even if they are experiencing troublesome physiological symptoms. This participant, an oncology nurse, provided some insight into this avoidant behavior,

By avoiding and not going to the doctor they can’t tell me anything bad is going on even if I know it is, so it is stupid, and it isn’t a good way to cope, but it is how I cope sometimes.

Other survivors in this sample noted avoidant behaviors in regard to emotional triggers, as well as talking about their illness and survivorship. Three survivors specified attempts to avoid places and people that remind them of their traumatic experiences with the illness. Three survivors indicated a preference for avoiding conversations about their diagnosis, treatment, and

survivorship and specified these behaviors are adaptive in some relationships with peers. One woman expressed her experiences of avoidant behaviors in the following passage,

I try to hide how I am feeling about being a survivor a lot of the time. I just always say “Yes, I’m okay,” even when I am not okay. I generally avoid talking about it so I don’t have to deal with it. Any of it. The feelings, the people not understanding. Just mostly want to avoid it all and try to be normal.

Medical Fears

Late effects and recurrence. All of the survivors who participated in this study specified a deep fear of late effects, the cancer recurring, or developing a second malignancy. Each participant described late effects from their treatments as being unpredictable and uncontrollable. Two of the participants noted that the late effects have significantly decreased the quality of their life. One survivor shared a photograph of how late effects have impacted her life, see Figure 7.

Figure 7.

The Battle Continues



Caption: This is the wound from brain surgery from a late effect of my cancer treatment as a child. There are a number of things I want people to know about surviving childhood cancer. One is that the battle is not over when the child beats the initial disease. Most of us will suffer serious, disabling, and life-threatening long-term effects, including secondary cancers and the risk of developing a new cancer increases with time. Even though we are physiologically cured, the illness follows us for the rest of our lives.

Healthcare professionals' misperceptions. A majority of this group of adult survivors of childhood cancer noted significant concerns and distress in regard to their current healthcare professionals. Each discussed feeling their physicians do not listen to their needs. Many participants specifically stated “we know our bodies and when something is wrong”. Several participants noted feeling dismissed by their practitioners at least once, and labeled as “hypochondriacs” or “anxious because I had cancer.” One survivor of acute lymphoblastic leukemia provided the following statement about how damaging these misperceptions can be,

When our current doctors have misperceptions about our health as an adult survivor of childhood cancer, it my health and my psychological health at stake. For example, I knew there was something wrong with my brain and nobody was listening and I felt like I couldn't tell anybody because they kept dismissing me - during that time I felt so helpless and hopeless. I knew something was wrong, I felt terrible. It was the worst feeling in the world. So, I think there is a lot at stake. I think doctors and people need to recognize that it cannot only hurt someone physically, but also it can really hurt them psychologically. I just really felt really hopeless and helpless. I don't know how much longer I could have gone on feeling that way knowing something was wrong and that no one was listening. It was terrible.

Needles, nausea/vomiting, scans. This sample of survivors largely did not experience fears or aversions to needles, but one survivor noted a significant fear and anxiety regarding needles, nausea/vomiting, and “scanxiety”. She noted a severe aversion to needles for a large portion of her survivorship, a conditioned response to nausea and vomiting, and significant anxiety regarding follow up scans. A survivor of nephroblastoma, or Wilm's tumor, is best expressed in her comment,

Nausea, needs, and MRIs, CT, or PET scans all produce a lot of fear in me. It is a big part of the childhood cancer journey. Just a certain level of anxiety that I don't think is ever going to go away. Mostly because all of these things remind us that something could be wrong, something could pop up again.

Paradoxes

Connection vs. Isolation. All of the participants discussed in their codifying of their photographs the paradox of connection and isolation. Each participant noted how important it is for them to experience authentic connections with others; however, they also reported this is difficult given the circumstances of their illness and survivorship. As the participants discussed this paradox, many noted the aforementioned psychosocial distress as a result of misperceptions of others, as well as avoidance of discussing their illness. One survivor of acute lymphoblastic leukemia provided the following statement,

It's a very sad paradox. Oh my goodness, it is just very sad. You know that people are with you and that they support you, but they don't really know what you are going through and they don't let you fully feel anything negative. So you hide a lot of emotions so you can stay feeling connected to them. So you feel connected and isolated at the same time. It's awful because feeling connected is so vital, so vital that you put away your true feelings to hold onto it.

Hope vs. Fear. A majority of the survivors reported the experience of a paradox between feeling hopeful and fearful. They expressed a great deal of hope for their future and, while this hope is joyful and comforting, they noted an equal experience of fear due to facing the uncertainties of late effects and possibility of recurrence. Each participant noted this paradox makes it difficult to plan for the future; however, they also cited that their personal growth allows them to be able to continue to reach their goals. Their experience of feeling hope and fear simultaneously is captured in the following passages,

There is so much to be hopeful for, but because I survived and so many good things continue to happen, but there is so much to fear and sometimes it feels like you are dying on the inside, but then something good happens that makes you hopeful again. I fear that if I lose hope I will have nothing else to hold on to.

And further,

A lot of people would phrase it like "it doesn't end once the treatment's finished", and that is very true. But it doesn't have to completely take over your life. Life's an ocean,

which it's actually most of the world, it's massive and can be quite scary. But there are many other things that you can swim through and enjoy while you're figuring out the rest.

Genuineness vs. Wearing a mask. Half of the participants indicated they were praised for being positive and strong; however, they specified that this was, and continues to be, an inauthentic expression of their actual experience of the illness and survivorship. All of the participants used words such as “hiding,” “avoiding,” “wearing a mask” and “just tell people what they want to hear”. Many of the participants described “wearing a mask” was an expectation of how they were supposed to behave and this resulted in this group of survivors’ suppression of their authentic emotions and experiences. As a result, several participants attributed a delayed response to the trauma of their experiences and a current inability to cope with negative emotions due to their identity of being an “inspirational childhood cancer fighter who is not allowed any other emotions besides positive ones”. One woman produced a photograph to capture this paradox, see Figure 8.

Figure 8.

Hidden Frown



Caption: I think that being genuine and being able to express what you really feel is one of the most healing experiences you can have. I think bottling it up and pretending that

you are not feeling the way that you are feeling does a huge injustice to a person. I was robbed with being genuine with how I felt about it, my cancer experiences, just because there is that expectation that I need to be brave and positive. And so, I put on that face and I was that person. I still am that person with a lot of people.

General conflicting emotions. Throughout the conversation and across the photographs codified by the survivors, a sub theme of conflicting emotions emerged. Participants noted an experience of conflicting emotions regarding their survivorship, including survivors' guilt. One participant described feeling grateful, yet guilty for surviving her cancer. Another participant described her struggle in this passage,

I feel grateful that I am alive, but I am still struggling to figure out why all of these late effects are happening. I'm certainly not grateful for those, they are dreadful and sometimes I wonder if being dead was the better option. But I know it's not, it's just conflicting feelings that I have about this whole thing.

Results of Interpretive Phenomenological Analysis

From the interpretive phenomenological analysis of the participants' detailed accounts of their experiences, a number of recurrent themes emerged (see Table 2). The themes include the following: 1) biopsychosocial stressors; 2) meaning-making; and 3) posttraumatic growth. As widely used constructs in the psychological literature, these themes have operational definitions that can be referenced in Appendix A. These themes are presented in a narrative format to provide an understanding of the disease—treatment—survivorship process this group experienced. While the process appears to be linear, the participants described their experiences as more cyclical in nature where dichotomies constantly co-mingle. The narrative begins with diagnosis and the onset of biopsychosocial stressors.

Table 2.

Superordinate and Subordinate Themes of IPA

Biopsychosocial Stressors
Existential Isolation
Dysregulation of Mood Due to Paradoxical Insights
Fear of Late Effects, Recurrence, & Second Malignancy
Healthcare Providers Uninformed to Survivor Needs
Meaning Making
Cultivating Gratitude
Creating & Accepting “New Normal”
Reappraising Cancer Diagnosis/Treatment
Posttraumatic Growth
Increased Altruism & Empathy
Increased Vitality
Emphasis on Developing Meaningful Relationships
Development of New Values

Biopsychosocial Stressors. This theme highlights the times participants described the pervasive, distressing impact of their cancer diagnosis on multiple domains of living throughout their experience with the illness, from diagnosis to survivorship into adulthood. Four subordinate themes emerged in this area, including existential isolation, dysregulation of mood due to paradoxical experiences, fear of late effects and recurrence, and current healthcare professionals being unaware of their survivorship needs. At the time of diagnosis, participants indicated awareness of several biopsychosocial stressors. One of the participants, Sam Talon, described her psychological and social experience with diagnosis:

Sam Talon: I was 14. I was in 8th Grade. I was very sad because I had just got my first boyfriend. We had made plans that day. It was high school orientation. My grandma calls me while I was in school and she says, “I am coming to get you and we have to go to a doctor's appointment. I was like, “No! I don't want to go.” She said, “No, I'm sorry we have to go and do this.” I'm thinking, why on earth do I have to go back to the doctor? I

said, "If the doctors are making us drive there to tell us the news, it means I have cancer, doesn't it?" My grandma said, "Yes, you do." I went to the doctor and I got put into a hospital room and I was mad and irritated. It was weird. I checked in and all these team of doctors came in and they start telling me about treatment this and treatment that. I'm just taking it, taking it, taking it, and then all of a sudden I just was so unfocused. I wasn't paying attention and I was just staring, and so I was like, "Hey, everybody get out." And so they all left, and I said "You too Grandma." And then, I severely cried into my pillow, and I've always been the type of person that never cried.

Orion, a survivor of acute lymphoblastic leukemia and mother of two young children, described a similar experience during her initial phase of diagnosis:

Orion: In the first couple of days after being diagnosed, I told my mom that she wasn't allowed to make phone calls in my room anymore. I couldn't listen to her cry. So she had to go and do the phone calls, that she's letting everyone know that I had cancer, she had to do that elsewhere. And she until that point, she was just sitting next to me calling people on the phone. So that is one example I remember of being, "You know what? I can be strong, but you need to not be like this around me." I think I told her, "It makes me think I'm going to die, you can't do it around me. I can't think like that if I am going to get through this."

Several important factors can be identified from these extracts. Sam Talon's initial reaction to her diagnosis was anger and irritation; however, she appeared to also conceptualize her reaction in the moment as unusual. As the physicians identified treatment options, Sam Talon began to feel her anger and irritation evolve into feelings of being overwhelmed and bombarded. This reaction was so intense that she was no longer able to focus and expressed an urgent need to be alone. In that aloneness she was finally able to express a deep, profound emotional reaction that she was unable to experience in the presence of others. It should not be forgotten that Sam Talon was a 14-year-old adolescent, who upon her diagnosis with cancer, verbalized the need to be alone to feel comfortable in expressing her authentic reaction. Both Sam Talon and Orion expressed the need to remove themselves from the emotional reactions of their family to maintain a degree of control over their experience with their initial diagnoses. Below, another participant, Edward, expressed his experiences with initial diagnosis and the impact his family had on his functioning:

Edward: And the day after that MRI my dad received a phone call I think the news hit him so hard that he couldn't really look me in the eye. I'll never forget the look on his face or the tears in his eyes. His crying and telling me that my leg was broken because it had been weakened because of a tumor that was in my bone. In my femur. So since he was crying, I got really scared. It was really hard. It was really hard to get my mind to accept what was happening to me. And not just me, but happening to my family. My family was so upset. A lot of the time I felt like I had to hide how I was feeling because I knew it would upset them. It is really hard to see your parents cry because they are sad or scared or whatever they were feeling at that moment. It was even scarier to know that the reason that they were scared or sad is because they fear you might die. But at the same time they tell you to think positively and always be positive about everything and tell you that everything is going to be okay, but they cry if you tell them you are scared. Because they are scared you are going to die and don't want to hear that you are scared that you might die. I didn't really get to talk to anyone about my fears of dying or not having a normal life any more if I lived.

This excerpt illustrates the simultaneous fear of potentially fatal biological pathology and the psychosocial experience of distress within a family system. Edward describes his fear as hard to understand or accept and, in the context of his family system, he found himself confused and overwhelmed by their emotional reactions to his diagnosis.

To some degree, all of the participants described the difficulty of comprehending and integrating their family's emotional reaction to their diagnoses and treatments. Just as Sam Talon described in her experience with initial diagnosis, Edward also expressed an immediate sense of existential isolation. Both of these survivors identified an initial motivation to hide their fear, sadness, and authentic experiences from their families. In these initial moments of diagnosis, participants described the onset of a lifelong experience of existential isolation.

Existential Isolation. Given the profound nature of a cancer diagnosis in childhood, one would imagine the importance of social support and interpersonal connection in creating healing and positive outcomes. The participants noted, however, the existential isolation they experience grows with time. Alicia described how her cancer diagnosis continued to divide her from her peers in a time of critical social development — middle school and high school.

Alicia: Going through cancer was an isolating experience. Since I had to be home schooled during 6th grade I missed out on meeting a lot of people in my new school. So the people that I really knew and were my clique in elementary school were separated into different buildings that year and then I was diagnosed with cancer, so I missed the socialization and the getting to know other people. By the time I came back I felt like an outsider. Everybody knew I had cancer and they weren't mean to me, but they didn't really socialize with me. I tried to be very outgoing and say hello and wave and smile at everybody. But really nobody really seemed to bring me into their group, so I continued to feel like an outsider. Everybody kind of knew me as the one really nice girl who is smart and has or had cancer. So I kind of felt like I had a label and that I didn't really fit anywhere. So I kind of lost out on social aspects of that part of my life. To top it off, I lost all of the friends I had in elementary school when I was going through treatment.

This extract draws our attention to the difficulties this group may have regarding relationship development. It would appear that after diagnosis and treatment are completed, Alicia returned to a social environment that further bolstered an overwhelming feeling of existential isolation from her peers. Her passage included her diligent efforts to connect with peers and to overcome the label of being a cancer patient. Unfortunately, it appears her efforts were to no avail and, thus, she continued a deep experience of isolation. Alicia's resiliency and desire to connect with others led to some degree of psychosocial distress. Another survivor, Jasmine, expressed how existential isolation has played a role in her overall experience with cancer and survivorship as an adult.

Jasmine: You have nobody that gets it, and like you're out there alone fighting a battle that not a lot of people understand. I was coming home from school crying every day. I would go down to my room, shut my door, and cry. Nobody knew, even my mom, I didn't tell anybody how alone I felt, but it was such a strong emotion that I went through then, and even now. Now I feel alone in the sense that people don't get what the after effects of childhood cancer are like. So it's just different feelings of loneliness based on where you're at in your life, but that feeling never goes away.

In this passage, we can expand upon the pervasiveness of isolation experienced by this group of survivors. As Jasmine reflected upon her history of existential isolation, she immediately connected it with her current psychosocial experience of aloneness as a childhood cancer survivor. In this excerpt, Jasmine does not explicitly state she has accepted isolation as

part of her psychosocial experience; however, she does not expect the feeling of profound loneliness to abate, but rather to evolve as she ages.

The sub-theme of existential isolation is a large piece of the childhood cancer survivorship narrative. All of the participants indicated deep emotional pain resulting from existential isolation. The participants experience of feeling separated from the world understandably impacts their psychosocial functioning. The most utilized coping mechanism indicated by the participants was to “bury it” rather than to tolerate it. Resultantly, the existential isolation experienced by this sample is buried deep within their existence, yet it appears to for recognition. For example, participants reported a vast sense of disconnection from others; however, in moments of experiencing existential isolation in its fullest they report craving connectedness and for others to realize and empathize with their plight. In fact, their narrative is abound with paradoxical insights such as the aforementioned example.

Dysregulation of Mood Due to Paradoxical Insights. This theme encompassed the numerous paradoxes noted by the participants throughout their account of diagnosis, treatment and survivorship. As seen in the results of the photovoice section, the paradoxes reported by the participants resulted in emotional dysregulation, including vacillating between feelings of gratitude and guilt. Alice, a survivor of rhabdomyosarcoma, described her journey between gratitude and guilt in the following excerpt:

Alice: I was aware I could die when I was six. I planned my funeral and the song I was going to have at my funeral. And I didn't realize that I felt guilty about surviving for a long time. When I was about 15 I started thinking about it a little bit, but quite abstractly. I was diagnosed with depression, but I didn't quite know why. I was trying to make everybody else happy before I could be happy because I had to figure out how I could get to good enough to live. Like the survivorship's something in terms of I can be both be kind of be grateful, plus also question and want to scream at the top of my lungs “how and why did I get to survive?” I still toy with being incredibly grateful for surviving and figuring out how and why, even though I shouldn't ask why.

In addition, Molly, a survivor of Ewing's sarcoma, provided the following insight during a particularly emotional part of her interview:

Molly: I think I might have been kidding myself or maybe hoping that you would see how surviving cancer is such a great thing and making sure you know how grateful I am because I want your paper to see how grateful I am, but sometimes I don't feel so great about all of this. I said I don't date and stuff because I'm worried about being judged for all of these things that cancer has done to me. Like I am damaged goods and no one will want me. [begins to cry]. Like who would want to kiss me with my mouth being so damaged by the treatment and reconstruction? Who would want to marry me if they think I won't live very long? Why would I be grateful for cancer making me feel like that? I am alive, so why do I feel like I might as well be dead if I don't get to experience living?

These passages identify the emotional dichotomy faced by all of the participants in this study. With the experience of existential isolation and the dysregulation brought on by paradoxical emotions, half of the participants indicated symptoms of depression and suicidal ideation. Of the participants who reported diagnoses of depression and suicidal ideation, three expressed having engaged in psychotherapy to minimize these thoughts and to gain additional insight into how cancer continues to affect their psychosocial functioning into adulthood. Further, those who indicated diagnoses of depression and suicidal ideation, cited the emotional paradox of feeling grateful for and simultaneously feeling resentful of the life cancer has given them as a significant contributing factor to their symptoms. Operating on the perception of the biopsychosocial impacts of childhood cancer survivorship, it appears the assault of the malignancy continues past biological cure. As this group of childhood cancer survivors continued in their survivorship, they expressed a notable increase in the fear of late effects, recurrence, and developing a second malignancy.

Fear of Late Effects, Recurrence, and Developing a Second Malignancy. In this theme, participants generally expressed that while they are alive, they continue to fear the occurrence and severity of their treatment late effects. This fear of recurrence and developing a

second malignancy is embedded in the expectations of surviving childhood cancer. Orion expressed how she was caught off guard when discovering how late effects would be a part of her life:

Orion: I mean, I think the hardest part of this specific dynamic in my story, for me, was being told, like, "I just have to get through chemo," you know? "All you have to do is survive cancer, and then everything can go back to being great. All you have to do is get through this." And so you're going through, like, the worst medicine you've ever had in your life and you feel like death warmed over and do it for a year and then you find out that that's not true, and by the way, there's all these side effects that nobody mentioned to you. And here you are and you have one major late effect that is worse than they've ever seen it in any other patient, and essentially you're disabled for life.

Orion was notably angry with her experience of physiological late effects, specifically severe degeneration of many of her joints. She attributed these physical late effects as being a major contributing factor in her experience of in psychological late effects, notably symptoms of depression and posttraumatic stress. These effects appear to be unrelenting and embed themselves as a regular part of childhood cancer survivorship; however, to the community at large, they are invisible. Alicia expressed a similar experience with late effects:

Alicia: There are long-term side effects of the non-targeted treatments, that we all have to deal with—and they can be quite devastating; and once you've experienced one, you have anxiety about developing others. So it is tough dealing with long-term side effects and when they happen all of those memories and feelings from childhood just rush back.

From this brief excerpt we can extrapolate the development of a late effect can imbue a cyclical process of fear and anxiety that only complicates the survivorship experience. As survivors develop a logical fear of additional debilitating medical maladies, they further entrench themselves in a fear that their body is unpredictable, therefore, constantly reminding them of their mortality. As the survivors continued to describe their survivorship experiences, it became clear they have a distaste for how their current physicians and healthcare providers approach their follow-up care.

Healthcare Providers Uninformed of Childhood Cancer Survivor Needs. This theme highlights the survivors' experiences with their current healthcare providers, who they overwhelmingly described as unaware of their special circumstances, including how to diagnose and treat late effects of childhood cancer treatment. Alice provided the following statement as she spoke of how her physician is largely unaware of the needs of adult survivors of childhood cancer:

Alice: We know our own bodies and we know our own minds. If they can be accepting to the fact that we can teach them, and I don't mean that in an egotistical way, just because I've had a doctor say turn around and say "I didn't even think about that as a possibility". And in the survivors try to recognize guilt, and or anxiety or depression. It's a lot more recognized than it was even about ten years ago, which is great. So if that continues, I just think it'd be fantastic and hopefully future patients and survivors will feel a bit more accepted.

This excerpt provides the reader with a perspective on healthcare that is evolving, yet calls for more focus on continued education and recognizing psychological symptoms post biological cure. The participants largely noted a desire for their medical professionals to develop a holistic understanding of their patients who are adult survivors of childhood cancer. Alicia also described an interaction with one of her healthcare providers that she believes would be different if they understood childhood cancer survivorship as being a rare, but profound medical experience:

Alicia; Yeah, cancer and other serious illnesses do cause you to be more anxious than other people who haven't dealt with that kind of illness. And our current doctors only seem to pick up on that part. When we say something is wrong, listen to us. We know our bodies. We have been patients since we are children and we know when something is off. We are not the typical person. I'm not the typical 28-year-old. My body is not going to read like a textbook because I have been through treatments that most people have not been through. My organs are not like other 28 year olds. I saw one nurse practitioner that saw me when I was having the pelvic pain from a uterus infection. She was so degrading to me. She said, "We don't look for zebras, we look for horses. You should know that if you are going to be a doctor."

Researcher: But you are a zebra.

Alicia: Yes! I am a zebra! I'm one of the zebras. I've had illnesses that are unusual and statistically much rarer than the average person gets. So doctors need to look harder and don't dismiss me.

In summary, the theme of biopsychosocial stressors encompasses existential isolation, an experience that seems to begin at the onset of the illness and continue throughout treatment and survivorship experiences. While the survivors experience this degree of isolation, they also seem to crave for others to understand their experiences with survivorship and to develop meaningful, authentic relationships with their families and peers. Further, their experiences with developing insight into their illness results in paradoxical, conflicting emotions. These paradoxical insights are embedded in the everyday life and biopsychosocial discourse of childhood cancer survivorship into adulthood. This fusion of isolation, paradoxical insight, and fears of late effects, recurrence, and secondary malignancy, resulted in half of the survivors experiencing a level of psychosocial distress culminating in suicidal ideation. While the survivors described their experience with pervasive and intense biopsychosocial stressors, they also described a simultaneous process of making meaning of their illness.

Making Meaning

Cultivating Gratitude. All of the participants discussed ways in which they feel grateful for their life and how they cultivate gratitude to manage survivorship. Edward expressed how he uses gratefulness:

Edward: When I think about having cancer and how it has impacted me, I just feel like cancer has given me a lot of things to be grateful for and an awesome perspective on life that I wish other people had, too. When I think of "why me?" I just remember how much I have gained from it and remember to be grateful for those things.

Similarly, Alicia describes below one of her cultivating gratitude practices:

Alicia: So I would go through a long list. "Thank you God for my eyes. Thank you God for my ears to hear. Thank you God for my arms that work. My hands that work. My fingers. My heart". I'd go through entire lists. I would go through every single thing that

was going right in my body. I think I am more thankful than before just because I am more aware of what all there is to be thankful for.

Being faced with the threat of death and intense medical treatments at such young ages, the survivors reported lives that were more meaningful as a result of their illness. These two excerpts draw our attention to not only the practice of gratitude, but also to how the survivors have made meaning of their illness by developing a deep appreciation for life. In Edward's passage, he speaks to the existential question, "why me?" and his answer to that question exemplifies how he has made meaning through being grateful for how his illness has positively impacted his life. Both of the above excerpts seem to illustrate how their cultivation of gratitude has changed since their diagnosis and treatment. In addition, it seems that both Edward and Alicia believe their deep appreciation for life is more profound than others might experience, and therefore, "being grateful" has become a part of their identity and a source of pride.

Creating & Accepting "New Normal". When the survivors recounted how they began to transition from childhood cancer patient to adult survivor of childhood cancer, they all discussed the idea of creating and accepting a "new normal." Elphaba, a college student, expressed it best in the following passage:

Elphaba: Generally, you sort of have a new normal. My life is normal now, but I don't think it will ever be exactly the same. Just because you have heard the words "you have cancer," it's sort of impossible to go back, but I think there's a healthy way to deal with it and an unhealthy way. I think I am doing it the healthy and to live life as normally as possible and accepting that it has changed because I had cancer.

Alice expounded upon Elphaba's passage, noting:

Alice: It's all I've ever known and it's also accepting of the natural process of life as well. Being transformed from childhood cancer and now being an adult, I guess recognizing that there is a new normal after diagnosis and the treatment and that what else am I supposed to do? Just accept it.

The survivors appear to be incorporating their experiences and reforming their beliefs about what is considered “normal” to regain contingency over their lives. One can imagine the lack of personal control and agency a childhood cancer patient might experience and how important it might be to develop a “new normal” that emphasizes those aspects of life. These passages exemplify the experience of creating and accepting that their lives have changed and the integration of their understanding of this “new normal” has regulated their global system of meanings, thus allowing them to reappraise the meaning of their diagnosis, treatment, and survivorship. Further, as Alice stated, this integration of the “new normal” appears to be a typical process of existence that cannot be altered, but rather accepted.

Reappraising Cancer Diagnosis & Treatment. Upon being diagnosed with childhood cancer, this group of survivors revealed a general process of reappraising the experiences of their diagnosis and treatment.

Jasmine: There are a lot of positives that can be pulled out of it, but you really have to search for it, it took me a long time to get there, and it just changes you so much. I sometimes think where would I be, and what would I be doing, and how would I be as a person had I not been through what I went through, because almost every decision I make in my life stems from what I went through. So it honestly wasn't until I got into nursing school that I found meaning in what I went through, because then it turned into something good, because of my story and my experiences I can help other people. Now it all kind of fits as to why I went through what I did. I wouldn't have the passion for this, or the desire to help other people had I not been through it.

And

Alice: Sounds so clichéd, but just makes me not afraid for what I want, whether that's family things or maybe long term goals. And making others aware of it and getting the momentum going to actually do something about it. And if I can use myself as a pathway for that, then I'll go ahead and do that. It doesn't mean that there are not moments when I don't completely fall off the train. I just have a process of figuring out how to get back on or stay on or get to the next station where it is all going to be okay.

These extracts describe the ways by which childhood cancer survivorship into adulthood can be understood via the continuous appraisal and reappraisal of the illness experience. These

passages illustrate the magnitude of feelings experienced throughout this process. Note the process as being difficult and emotionally painful, yet the end result appearing to be consistent with a strong feeling of worthiness and passion for using life to create goodness in the lives of others. It appears that survivors' psychosocial adjustment is influenced by their ability to reappraise their diagnosis and treatment.

In summary, this theme illustrates how adult survivors of childhood cancer move through a process of making meaning of their cancer diagnosis—treatment—survivorship experiences. The meaning-making process appears to be cyclical and somewhat distressing. The survivors cultivated gratitude to mediate the distressing nature of meaning-making. As the process is cyclical, it can account for some of the continued biopsychosocial stressors detailed in the previous themes. The participants' willingness to continue engaging with the meaning-making process is evident and appears to aid in psychosocial adjustment, which further impacts the outcome of posttraumatic growth, the last major theme of this analysis.

Posttraumatic Growth

Given the currency that a cancer diagnosis can have, and indeed the notion of seeing life from a more grateful and hopeful point of view, it is not surprising that amongst the participants there was the potential for personal growth. This group of survivors continually expressed multiple domains of personal growth including increased altruism and empathy, increased vitality, an emphasis on developing meaningful relationships, and development of new values. Having experienced the threat of death, as well as the continued threat of late effects and second malignancies, the survivors of this study expressed a depth and magnitude of emotion regarding how they use that knowledge to increase the meaning of their current existence.

Increased Altruism & Empathy. Across the interview data, the participants provided several stories, emotions, and behaviors that indicated an increased focus on altruism and gaining advanced empathy for others as a result of having survived childhood cancer, a trend that seemed to increase in importance over time. As Alicia says:

Alicia: I know that I can empathize in a way that many people can't because of what I have gone through. I also think that because I know what it is like to be sick and how important it is to have someone to listen to you.

Sam Talon also expanded upon how her level of empathy developed as a result of her illness:

Sam Talon: I'm more empathetic to other people who are going through dark times, where before cancer I just thought dark times were normal and that everyone went through them like I did. So I didn't really care as much, but cancer made me realize that pain is everywhere, it is good to care and talk to people about their pain and try to understand that pain even though you aren't going through it yourself.

Further, Orion elaborated on the importance of empathy

Orion: I just, I think I have a lot of empathy for people who have unseen struggles because a lot of my struggles have been invisible.

Alice expounded on how she experienced an increase in altruism and managing how she values the well-being of others:

Alice: We have to decide what to do with the time that was given to us and just sometimes I hit a wall with that, but the desire to do something for others is there and that's what's pushed me through. And that, the desire to help others, it will make me get back up again somehow. There is a true sense that other people who aren't childhood cancer survivors don't understand, and it makes it worthwhile to help that group try to help others like me feel less alone. It relates back to feeling guilty for surviving cancer and how I could do something about it so I could help other people that are like this.

What we can deduct from these passages is not only the survivors' increased empathy in their survivorship experience, but also their deep, profound desire for others to empathize with and understand their continued suffering as a survivor. It appears the increase in empathy and altruism also comes with an increased desire for others to experience that same level of empathy. They want to provide others the empathy they feel others lack for them. Their views and

behaviors changed to embody the person they wish they would have to talk to in times of distress. This group of survivors not only clearly values genuine human connection, they crave it, in what appears to be a direct contradiction to their experience (isolation and avoidance) as a childhood cancer patient. Expanding upon the narrative provided thus far, the survivors experienced their family and support systems as portraying an inauthentic expression of self, as well as the childhood cancer patient being praised for displaying an inauthentic expression of their own thoughts, feelings, and experiences during diagnosis, treatment, and survivorship.

Increased Vitality. The survivors expressed changes in their feelings of vitality during and after their disease treatment. This theme addressed the times survivors talked about a new appreciation and energy to live a full and meaningful life. Many of the participants noted how a sense of urgency led them to become more active and develop an approach to living that maximized opportunities to feel worthy of the life they have been given. As Orion stated:

Orion: There's some sort of vitality that comes with the urgency of being diagnosed with cancer and then with, like, the terminal kind of thing hanging over my head that I think probably came from that. It's just like, "Let's grab life by the horns and run."

Alice further expanded in the passage below,

Alice: It's not what everyone said, you know? You can carry on for them and you can carry them with you. It's like I am living more fully to honor those who died. And I don't know how familiar you are with Peter Pain, but that quote "to live would be an awfully big adventure", makes me want to live a good life.

Several important issues should be noted from these brief extracts. Orion described how urgency influences her to live more actively and meaningfully. This sense of urgency is also associated with the threat of recurrence and, therefore with death, resulting in a tendency for adult survivors of childhood cancer to seek out experiences that contribute to their cyclical process of making meaning and mediating biopsychosocial stressors. Further, Alice expressed her increased vitality as a way to homage to those who died as a result of childhood cancer. This

form of remembrance appears to give Alice the drive to live more fully and contributes to her meaning making processes.

Emphasis on Developing Meaningful Relationships. Another area of posttraumatic growth prevalent in the verbal data was the importance of developing meaningful relationships, a desire that seemed to increase across the course of survivorship. Elphaba highlights this emphasis with the following statement,

Elphaba: My relationships have gotten a lot better. Better quality if that makes sense. So better quality relationships and more meaningful relationships with new people that I wouldn't have met otherwise. I think the relationships that I've developed helped me see the positive outcome of having cancer.

Below, Alicia shares how meaningful relationships have impacted her experience and ultimate psychosocial behaviors

Alicia: I am just so grateful and happy that I was fortunate enough to have contact with such amazing people in my life. Also, I think them sharing their light with me has inspired me to share my light with others.

In the following statement we can see how Sam Talon expresses the importance of her relationships being driven by altruism, rather than obligation:

Sam Talon: I really, really value friendship. I am really sensitive about my relationships, especially my friendships. I will make sure I do make friends and I am able to keep them. I really, really value having people in my life, that are in my life because they want to be, not because they have to be.

From a different perspective, Molly indicated some interpersonal struggles; however, she emphasized the meaningful relationship she finds in her faith in the excerpt below;

Molly: I don't really have that many friends now and I am thankful that my relationship with the Lord is so strong, otherwise I would feel really alone. It is the most meaningful relationship I will ever have, my relationship with Jesus Christ.

This sub-theme is filled with stories and descriptions of how meaningful relationships are emphasized in survivorship. Across the history of survivors' relationships, they have

experienced existential isolation leading to varying degrees of distress, as well as an increased desire for meaningful relationships. The importance this group places on meaningful relationships is not only understandable, but within the survivorship context is interpreted as an appropriate way to cope with the isolation they experienced as a childhood cancer patient as well as the isolation they continue to experience in survivorship. There also seems to be a rapid development of the survivors' definition of what makes a meaningful relationship from the onset of the diagnosis and treatment of the malignancy. They develop an understanding that cultivating meaningful relationships requires vulnerability, which mirrors the experience of being vulnerable to disease and death. Due to this trigger, it may be difficult to break down barriers needed to develop the meaningful relationships they seek. Specifically, adult survivors of childhood cancer appear to redefine their relationships by the new values they have developed from their illness experiences.

Development of New Values. A majority of the participants described an overall change in their values throughout their meaning-making processes. Edward clearly outlines this experience as he describes what he has learned from his illness:

Edward: I have learned to be more flexible and I have learned that things can change and to be okay with it when something doesn't work out how I planned. I guess I account for change now so I don't get rooted in a dream like I did before. I still have dreams and aspirations for the future. I value flexibility now. Now I just don't plan my life so narrowly and to make contingency plans along the way so I don't feel so thrown out of whack when something doesn't go according to plan.

Orion also illustrated this learning experience:

Orion: It has taught me so much, and it has informed the majority of my life at this point, right? And so I've learned living, doing the big things, not waiting for the big things, not putting off family or marriage or the schooling that I want to do or the learning that I want to do, going after life because, who knows, right? Who knows how long I have now? Because it feels like I'm living with a terminal diagnosis with no clear disease and no clear timeline, but there's this terminal diagnosis hanging over me because of the risk of secondary cancers. It makes me extremely passionate about everything that I'm doing

and my values changed to include those things that I am passionate about now, like family and friends and my education. And the value of living in the moment.

Alice also described how she developed new values as a process of working through survivors' guilt:

Alice: I wouldn't dance. I would go out with my friends at school, but I wouldn't dance. I couldn't let myself dance because I might be enjoying living. And relationships, I wanted them like everyone did, but I wouldn't let myself. In the start of the relationship, even liking someone, I'd be like "No, I can't do that". Now it's more about not sweating the small stuff and being patient. Sometimes you get answers and even when you don't get answers, learning to be comfortable with that and focusing on other things. I still value benefiting others, but it is different now because I can enjoy living.

The interpretation of these passages includes the understanding that experiencing posttraumatic growth is the turning point in the narrative, a point at which the survivors are psychologically changed. This process of developing new values is identified on several occasions and several levels in each participants' overall narrative. The development of new values appears to be a function, as well as an outcome of the survivors' meaning-making processes — each process serving to inform the other. The passages above reveal how developing new values has also aided the survivors in creating a repertoire of coping skills to use when faced with unrelated life change and psychosocial stressors.

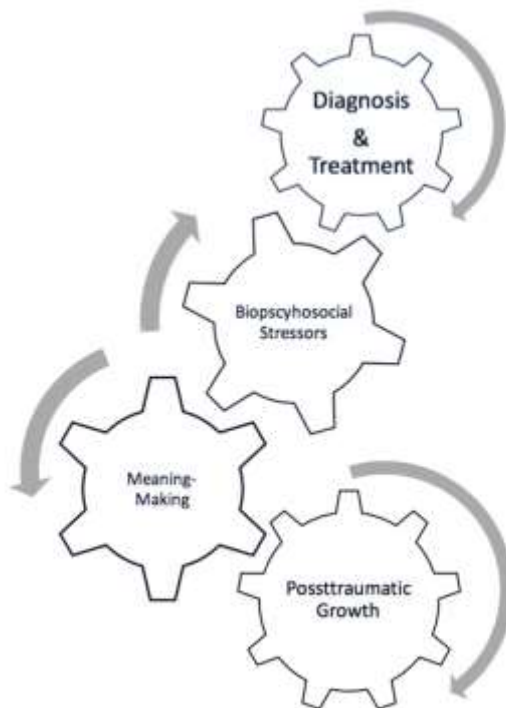
Contextual Model of Childhood Cancer Survivorship into Adulthood

The data provides a developmental perspective of the entire diagnosis—treatment—survival process. A more complex, contextual model is derived from the photovoice codes provided by the participants, as well as the IPA of the data. While the survivors report making meaning of their illness which resulted in posttraumatic growth, there are clear parallels with the theme of biopsychosocial stressors with much darker inter/intrapersonal dynamics at play. The process of meaning-making appears to be cyclical in the face of newly developed late effects and continuous reminders of the disease.

Diagnosis and treatment spurns the shattering of childhood cancer patients' assumptions of their global meanings. This incites a multitude of biopsychosocial stressors that are pervasive throughout treatment and extend beyond biological cure. The crux of the model is the continued presences of these biopsychosocial stressors that make the meaning-making process, while distressing in and of itself, a cyclical process. When the survivor makes meaning of his or her illness, he or she is likely to experience posttraumatic growth; however, due to the continued biological threat and existential isolation, the process continues. The paradox of adult childhood cancer survivors' experiences are summed up in this model. While striving to live meaningful lives full of experiences that match their newly developed values, they continue to struggle with feeling connected and understood.

Figure 9.

Conceptual Model of Childhood Cancer Survivorship into Adulthood



Note. This model includes meaning-making (Park 2010) and posttraumatic growth (Tedeschi & Calhoun, 2004) processes.

Without the continued presence of biopsychosocial stressors related to the initial trauma of diagnosis and treatment, adult survivors of childhood cancer would be more likely to sustain the meaning made of their illness and fully benefit from posttraumatic growth. While it is impossible to eliminate biopsychosocial stressors from the human experience, we should focus on reducing their occurrence in this population. In the same vein, we cannot eliminate the biological fear of late effects, recurrence, and developing a second malignancy; however, there are clinical implications for how healthcare professionals can mediate the psychosocial aspects of childhood cancer survivorship into adulthood.

Discussion

The combination of photovoice and interpretive phenomenological analysis worked well to explore the lived experiences of adult survivors of childhood cancer. The visual expression of the data aided participants in conveying deeply emotional, yet abstract, concepts embedded in their daily life. Being empowered to share their personal narratives through visual mediums may have revealed experiences that may have not been accessed through other means or methodologies. By allowing the participants to employ metaphorical representations of their history and current functioning we achieved a level of insight into how they experience survivorship, affording us the opportunity to learn from the actual lived experience of childhood cancer through imagery.

Photovoice empowered the participants to be part of the research by developing their own themes for their photographs and experiences, of which the IPA was able to build upon. The use of IPA bolstered the scientific rigor of the photovoice methodology and allowed the results to develop a conceptual, developmental framework for how the survivors made meaning of their illness further providing the researchers with an opportunity to examine, in detail, the

experiences of adult survivors of childhood cancer. The analysis has demonstrated, first and foremost, that childhood cancer survivorship into adulthood is anything but a linear model of recovery after biological cure of the disease. From this analysis, adult survivors of childhood cancer experience continuous biopsychosocial stressors from the onset of the illness, including a cyclical meaning-making process that contributes to these stressors. Each participant, however, also experienced a degree of posttraumatic growth. Although some of the themes of the photovoice and IPA results may seem obvious, they have profound implications for how healthcare professionals could theorize and understand the development and transition of childhood cancer patients into adulthood.

This study highlighted the voices of adult survivors of childhood cancer by providing their specific analysis of their own photographic data. This gave rise to an additional knowledge and insight about the experiences of childhood cancer survivorship into adulthood in a way that has not been previously expressed in the literature. Moreover, when talking about survivorship, the participants highlighted a range of very powerful and complex meanings and emotions. For the most part, these powerful meanings related to both their physiological health as well as their mental health. These findings point to the limitations of the static and linear research methodologies that have been previously employed to develop an understanding of childhood cancer survivorship. They highlight complexity, ambiguity, and variability within the survivorship experience, something that is difficult to capture with cross-sectional quantitative research designs.

First, a note of caution. This study included only eight people and, therefore, is not generalizable to the larger population of adult survivors of childhood cancer. Though the sample size is small, there is value in delving deeper into the particular as an avenue to bring us closer to

the universal (Warnock, 1989). Further, this study included nearly all females, with only one male represented in this sample, and there were no ethnic or racial minority participants. Lastly, we also acknowledge our biases that may have impacted the analysis and, therefore, the findings. Specifically, all of the researchers have had the privilege of caring for adults with cancer and we may have had predisposed beliefs about how survivorship looks in the larger cancer survivorship populations.

Additionally, while photographs are easy to capture, they are difficult to analyze and summarize due to the complexity of the data. Another limitation of the current method from a qualitative standpoint is the use of transcriptions of audio-recorded data, which limits the analysis of nonverbal behaviors such as gestures, facial expressions, and vocal tones (pace, intonation, volume). Therefore, some of the richness of communication is lost (Polkinghorne, 2005); however, the presence of the visual image along with the transcript minimizes this limitation. Despite the limitations of the study, the implications remain profound and congruent with previous research findings.

These research findings support Parry and Chester's (2005) qualitative study, which noted childhood cancer survivors reporting the development of new values, and that most children and adolescents who survive childhood cancer do not only recover but surpass their previous psychological and social functioning. Findings also upheld Duran's (2013) research that identified five themes of posttraumatic growth, including: 1) meaning-making, 2) appreciation of life, 3) self-awareness, 4) closeness of family togetherness, and 5) a desire to pay back society. Likewise, the findings of Haase and Rostad (1994), which discovered that the completion of biological cancer treatment resulted in a celebration full of hope, whilst also being laced with fear and continued uncertainty, are supported. Lastly, Cantrell and Conte's (2009)

results, which explored the experiences of transitioning off treatment and into early survivorship and described childhood cancer survivorship as a paradoxical existence, are bolstered by our findings. The results of this study add a broad understanding of the developmental, contextual nature of childhood cancer survivorship into adulthood.

Existing literature has portrayed childhood cancer survivorship into adulthood as linear, oversimplified, descriptions of adjustment vs. maladjustment. This data, however, revealed congruent, cyclical, and simultaneous experiences of biopsychosocial distress, meaning-making, and posttraumatic growth. The concepts appear to be integrated and do not exist independently. Our model reveals how the continuous biopsychosocial stressors of survivorship influence the meaning-making processes and experiences of posttraumatic growth in this population. In Park's (2010) meaning-making model, the author proposes both global and situational meanings are implemented when a person is faced with a challenging event and are forced to re-appraise that event (see Appendix S). Further, this re-appraisal begins on a situational basis and moves toward the global basis (Park & Folkman, 1997). The challenging event leads from an appraisal of the situation, to an appraisal of the situational meaning, and then an attempt is made to align situational meaning with global meaning. Hence, the goal of meaning-making is to develop a congruency between situational and global meaning.

Our contextual model of childhood cancer survivorship into adulthood is congruent with Park's (2010) meaning-making model; however, there is one notable contrast. Due to the continuous threat of recurrence, developing a second malignancy, and the unpredictable onset and severity of late effects, adult survivors of childhood cancer are consistently re-engaging in distressing meaning-making efforts and, therefore, struggle to fully develop a congruency between situational and global meaning. Hence, our model describes the meaning-making

process in adult survivors of childhood cancer to be an ongoing reappraisal of meaning(s) made and these meaning making processes interact with the continuous biopsychosocial stressors of survivorship and elements of posttraumatic growth. This difference is important to note, as adult survivors of childhood cancer report and make meaning of their illness, a process that has contributed to their experience of posttraumatic growth.

Our findings also fully support Tedeschi and Calhoun's (2004) model of posttraumatic growth (see Appendix T). Their model proposes a process including individual characteristics, self-disclosure and social support, and significant cognitive processing of the traumatic event. The culmination of this process results in a life narrative that is developmental and continuous in nature (Tedeschi & Calhoun, 2004). In their model of the PTG process, 'deliberate rumination' is akin to the meaning-making processes described by Park (2010). Tedeschi and Calhoun also noted the presence of posttraumatic growth does not indicate a lessened degree of psychosocial distress. In fact, some degree of enduring psychological distress may be necessary to not only set the process in motion, but may also enhance and maintain the experience of posttraumatic growth.

Consistent with the aforementioned theory, this group of survivors expressed continuous biopsychosocial stressors, prolonged threats to their health status, and cyclical engagement in meaning making processes, and yet they retained a narrative about with the conveyance of posttraumatic growth. Our results also do not indicate posttraumatic growth is an outcome that reduces psychosocial distress, which is also supportive of Tedeschi and Calhoun's model as it does not predict such a relationship. Posttraumatic growth appears, however, to contribute to the overall continuous and integrated experiences of biopsychosocial stressors and meaning-making processes experienced by adult survivors of childhood cancers. Results of this study also fit well

with Tedeschi and Calhoun's description of posttraumatic growth as a painful process that allows for the appreciation of paradoxes and is the consequence of multiple attempts to recreate basic cognitive guides for living (2004).

Clinical implications of our results include a call of mental health and healthcare professionals to develop an understanding of the unique needs of adult survivors of childhood cancer. Specifically, physicians need to develop an understanding of not only the physiological late effects of their patients with a history of childhood cancer and treatment, but also the psychological implications of their survivorship. The results of the photovoice data indicated several participants' having difficulties with their medical providers and they call for increased awareness of late effects and for more attention to be paid to psychological aspects of survivorship. From the literature regarding the doctor-patient relationship and doctor-patient communication, we understand that positive interactions are correlated with positive outcomes (Sapolsky, 1965) and negative interactions are correlated with more unfavorable outcomes including lack of patient adherence (Golin, DiMatteo, & Gelberg, 1996) and poorer self-reported health (Stewart, 1995). Therefore, it is important for the medical community to develop an understanding of this population's unique experiences to improve health outcomes. Further, adult survivors of childhood cancers are following up with medical providers for routine care and these medical providers are in a prime position to recognize the need for additional psychological treatment and refer the survivor for psychotherapy.

For mental health professionals, as adult survivors of childhood cancer retell the story of their illness, we should consider how their emotional and behavioral responses may be understandable reactions to a dreadful experience. Further, special considerations should be placed on helping the patient recognize and manage constraints in their social systems, as well as

explore existential concerns and the paradoxes integral to the experience of posttraumatic growth. It is important to note that clinicians tend to focus on symptom reduction and, therefore, unintentionally fail to assist clients as they reorder and restructure situational and global meanings of their illness. Based on the results of this study, clinicians may consider treating clients who survived childhood cancer from a narrative perspective and assist them in constructing a narrative of their illness that accommodates the childhood cancer experience. From an evidence based perspective, cognitive processing therapy (CPT) may also be beneficial in assisting the client in restructuring their beliefs about their traumatic illness.

What may be the most important clinical consideration, however, is the importance of appreciating the difficulty and the struggle this population experiences as they engage in an ongoing cognitive process and make meaning of their childhood cancer. While this population may report making meaning and experiencing posttraumatic growth, we must appreciate the paradoxical and continuous nature of these processes and empathize with the cognitive and emotional struggles of this group of cancer survivors. Specifically, clinicians should develop an understanding that posttraumatic growth is not an outcome that implies a reduction in symptoms, rather, it contributes the overall reported paradoxical existence of these survivors that leads to recurrent psychosocial distress.

Future research using mixed methods combining quantitative instruments like the Posttraumatic Growth Inventory, the Life Stressor Index, the Impact of Events Scale, and/or the Dyadic Coping Inventory with experiential qualitative methods like photovoice and IPA, could further strengthen our understanding of the unique experiences of childhood cancer survivors into adulthood. Longitudinal work, however, will be the best avenue for mapping the process and trajectories of meaning-making and posttraumatic growth in adult survivors of childhood

cancer. Given that meaning-making and posttraumatic growth unfold in their individual social contexts, a fruitful line of investigation would include studying adult survivors of childhood cancer in broader, cultural frameworks.

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Appendix A

Thorough Review of the Literature

The following section will review the available theoretical and empirical literature regarding childhood cancer, meaning-making, and posttraumatic growth as they pertain to the research question of this study. Specifically, this review covers the effects of childhood cancer, theoretical bases for understanding meaning-making and posttraumatic growth, empirical findings about existential meaning-making and posttraumatic growth, and a summarization of the importance of this study.

The Effects of Childhood Cancer

Each year, in the United States alone, more than 12,000 children and adolescents are diagnosed with cancer (Bhatia et al., 2007). Fortunately, the 5-year survival rate is increasing and resulting in a growing population of childhood cancer survivors. In 2010, there were an estimated 379,112 survivors of childhood cancer in the United States (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). As the rates of survival from childhood cancers increase, questions regarding the psychological implications of survival from childhood cancers have begun to arise. Literature is developing concerning psychological late effects (late occurring outcomes that develop beyond five years after cancer diagnosis).

Even with a biological cure, Meadows (1991) found survivors of childhood cancer could be 10 to 20 times more likely to develop a second malignancy in comparison to an age-matched individual in the general population. The Greek myth of Damocles nicely illustrates the fear about the recurrence of cancer. While Damocles had a taste of luck and fortune, he found himself looking up at a sword suspended from the ceiling just above his head, held in place by a single horsehair, threatening to end his life at any moment. Similarly, adult survivors of childhood

cancer may feel as if they had tasted luck and fortune in surviving their illness, however, the risk of recurrence and late-effects may leave this population in fear of further life threatening situations akin to the sword of Damocles. Such fears include late-occurring outcomes that develop beyond five years after a cancer diagnosis, including a second malignancy, organ damage, infertility, and cognitive impairments. These late-occurring outcomes are known as “late effects” (Bhatia, 2007).

Late effects are physiological and psychological in nature and as many as two-thirds of childhood cancer survivors experience at least one late effect (Bhatia, 2007). Physiological late effects are heavily researched in comparison to psychological late effects (Brougham, Kelnar, Wallace, 2002; Meadows, Gallagher, & Brunin, 1992; Mulrooney, 2010), although literature is developing in regard to psychological late effects with most of the studies investigating areas of posttraumatic stress. Multiple studies have found up to 50% of young adult childhood cancer survivors experience intrusive, avoidant, and arousal symptoms of posttraumatic stress, which would significantly hinder their psychological wellbeing (Hobbie et al., 2000; Langeveld, Grootenhuys, Voutes, & deHaan, & Bos, 2004; Rourke, Hobbie, Schwatz, & Kazak, 2007). Additionally, Zeltzer et al. (1997) found adult survivors of childhood cancers exhibited significantly more symptoms of depression and tension in comparison to their siblings. A report from the Childhood Cancer Survivor Study covers more specific risk factors for poor outcomes in psychological wellbeing including poor health related quality of life (Zeltzer et al., 2009). These risk factors include being female, lower education levels, being unmarried, having an annual household income of less than \$20,000, being unemployed, no health insurance, presence of a major medical condition, and having had radiation treatment to the brain (Zeltzer et al., 2009).

Seitz et al. (2011) conducted a study regarding life satisfaction in adult survivors of childhood cancer and found the survivors reported significantly less satisfaction in comparison to the control group. Further, Sharp et al. (2007) reported depressive symptoms to be a major contributor to poor outcomes in psychological wellbeing in this population. Considering the increased risk for posttraumatic stress, negative moods, tension, and depression, the literature also expands upon the consequences of such symptoms, including suicidal ideation.

One study has shown adult survivors of childhood cancer, in comparison to a non-cancer control group, are significantly more likely to report suicidal ideation (Zebrak et al., 2002). Zebrak et al. (2002) conducted a study on psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's Disease, and Non-Hodgkin's lymphoma. The sample of 5736 survivors and 2565 sibling controls was assessed with a brief psychological health status using items from the Brief Symptom Inventory (BSI). The results indicated in comparison to their siblings, childhood cancer survivors were 1.6-1.7 times more likely to report symptomatic levels of depression, somatic distress, and suicidal ideation (Zebrak et al., 2002). Similarly, Recklitis, Diller, Li, Najita, Robison, and Zeltzer (2010) conducted a study using the BSI-18 to assess for increased likelihood of suicidal ideation in the population of adult childhood cancer survivors. With a sample of 9,126 participants, and a 2,968-sibling control group, results indicated adult survivors of childhood cancers were at significantly increased risk for suicidal ideation when compared to the sibling control group. Specifically, 7.8% of survivors reported suicidal ideation in the week before completing the BSI-18, in comparison to 4.5% of the sibling control group. The survivors who reported current poor health status had the highest prevalence of suicidal ideation with cancer-related pain being significantly associated with higher prevalence of suicidal ideation (Recklitis et al., 2010). The significant minority of those survivors reporting

suicidal ideation is a serious concern as it is a risk factor for self-destructive behaviors and indicates severe emotional pain.

Emotional pain is a side effect of highly challenging life events and trauma. From a clinician's perspective, the most appropriate goal for their clients is the reduction of subjective distress. Clinicians should note, however, that subjective pain and growth might coexist by making meaning of the traumatic event (Yalom & Lieberman, 1991). Finding meaning has a long history in the psychological health literature since the publication of Frankl's (1963) account and observations during his imprisonment in Nazi death camps.

Throughout history, many thoughtful psychologists including Fromm (1947), Frankl (1961), and Yalom (1980) have written about the possibilities of positive effects and change that occurs as a result of stressful life events, like childhood cancer diagnosis and treatment. Despite a long history of studying meaning-making, it has only been in recent years that researchers have begun to systematically investigate and understand the positive outcomes of meaning-making (O'Leary & Ikovics, 1995; Tedeschi, Park, & Calhoun, 1998). These studies have been driven by existential and crisis theories, which both focus on the effects of meaning-making throughout life. These theories are considered in the following pages in regard to survival of childhood cancer.

Theory and the Experience of Illness

Multiple theories attempt to describe the experience of illness (Coward, 2000). Frankl (1963) and May, Angel, and Ellenberger (1958) have paid attention to the notion of existential meaning in relation to illness and emotional suffering. Specifically, there are two theories that drive this study and explicitly address existential meaning and subsequent posttraumatic growth

for people who suffer from disease. These theories are existential theory (Yalom, 1980) and crisis theory (Coward, 2000; Janoff-Bulman & McPherson, 1997).

Existential Theory

Frankl's (1963) influential writings about his experiences in Nazi concentration and death camps described people who were able to find meaning in life, despite the horrors of their circumstances, were most equipped for survival. Since "Man's Search for Meaning" was published, the notion of finding meaning has been accepted in psychological literature as related to the psychological experience of adversity. Frankl (1963) suggested the inquiry "What is the meaning of life?" has become the ultimate question of human existence and drives human purpose. Subsequently, existential theory was developed and is the most recognized theory regarding issues of meaning and meaninglessness and further provides a general summary of ultimate human concerns including our mortality (Yalom, 1980). At its core, this theory emphasizes the centrality of a quest for meaning and purpose.

Existential therapists argue that how a person answers questions regarding meaning can result in despair, depression, and a sense of meaninglessness or result in adjustment through personal growth (Wong & Fry, 1998). Yalom (1980) described the process of questioning meaning as a fundamental component of the human experience. Meaning as defined by Reker and Wong (1988) is, "the cognizance of order, coherence, and purpose in one's existence and the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfillment" (p. 217). Reker (1992) further described existential meaning as, "a dual component construct defined as having life goals, having a mission in life, having a sense of direction from past present, and future, and having a logically integrated and consistent understanding of self, others, and life in general" (p. 20). After a cancer diagnosis and during cancer treatment, it is likely a patient will

begin to question their existential meaning in terms of order, coherence, and purpose as they attempt to make meaning of their experience (Coward, 2000).

Singer (1992) differentiated between a cognitive sense of meaning (i.e., search for an explanation or clarification about life) and an emotional sense of meaning (i.e., feelings that guide behavior). When endangered by a life-threatening illness, the cognitive evaluation of the meaning-making process influences psychosocial adjustment and quality of life (Butler, 1995). This cognitive evaluation could result in posttraumatic growth and feeling life is meaningful rather than meaningless. Reker (2000) described a person with a high level of perceived existential meaning as someone who has “a clear life purpose, a sense of directedness, strives for goals consistent with life purpose, feels satisfied with past achievements, and is determined to make a future meaningful” (p. 41).

Clinicians working with cancer patients and/or cancer survivors are often aware of the existential issues these populations ultimately struggle with during and after the illness (Loscalzo & Brintzenhofesec, 1998). Mental health clinicians who espouse an existential theoretical orientation would most likely argue the way a person responds to an existential crisis and answers questions related to meaning would impact psychosocial outcomes. Specifically, the psychosocial outcome could either be adjustment, growth, and increased life satisfaction or despair, depression, and a sense of meaninglessness (Wong & Fry, 1998). Existential meaning is certainly a pertinent issue for cancer patients and survivors as it considerably impacts psychosocial adjustment to the illness.

Crisis Theory

Crisis and trauma are words that are easily associated with a cancer diagnosis, both of which also define the second theory driving this study. The basic principle of Janoff-Bulman and

McPherson's (1997) crisis theory is that traumatic events destroy, or shatter, a person's assumptions about living in a fair, safe, and just world, which leads to subsequent questioning of the meaning of life at a global level. This theory conceptualizes the crisis as the primary incentive for someone to struggle and address issues of meaning (Janoff-Bulman & McPherson, 1997). Being diagnosed with cancer can induce a crisis-like state, especially during adolescence through middle age when the fear of death tends to be higher (Dennis, 2009). The impact of the trauma, or crisis, causes depletion in the sense of meaning and the person has to make intentional efforts to regain the sense of meaning they lost (Janoff-Bulman & McPherson, 1997). The experience of this meaninglessness as well as intense efforts to regain a sense of meaning can cause the person to experience posttraumatic stress and other psychological symptoms (i.e., depression, suicidal ideation). Additionally, Janoff-Bulman (2004) proposed three explanatory models of posttraumatic growth. These three models include strength through suffering, psychological preparedness, and existential reevaluation. The first of the models, strength through suffering, is the most apparent in the culture in the United States (Janoff-Bulman, 2004).

Janoff-Bulman (2004) proposes that our beliefs regarding the proverb "what does not kill us makes us stronger" provides an implied message that there is a redemptive value of suffering. This thought underscores the first model, which states posttraumatic growth occurs through our belief that we grow stronger through our trauma experiences. In the example of cancer, survivors become aware of their previously unknown strengths and, therefore, develop new coping skills to use in future experiences of trauma (Janoff-Bulman, 2004). The second model proposed regards psychological preparedness and suggest, "survivors are not only better prepared for subsequent tragedies, but as a consequence, are apt to be less traumatized by them as well" (p. 31). The third model emphasizes existential reevaluation and describes humans as

creatures that create meaning whose assumptions about meaning are significantly affected by trauma (Janoff-Bulman, 2004). Survivors of trauma, including young adult survivors of childhood cancer, do not only want to understand why their cancer happened, but why it happened to them.

Summary of Theories

Existential theory and crisis theory both help explain childhood cancer's potential impact on psychosocial outcomes regarding meaning-making and posttraumatic growth. Each theory bolsters the support for exploring the meaning-making process and how it could result in posttraumatic growth after surviving childhood cancer. Making meaning of a cancer diagnosis is an important factor in a patient's adjustment to illness; however, empirical approaches to understanding and measuring psychosocial adaptation have largely omitted this construct. Therefore, expanding the literature on the meaning-making process and its contribution to posttraumatic growth is a step forward in understanding the experiences of adult childhood cancer survivors.

Making Meaning

Interest in meaning-making in the face of illness is growing. Research, however, is hindered by the inherent conceptual and methodological limitations surrounding a construct that is not easily measured (Park, 2010). The previously covered theories focus on issues of meaning in regard to illness. Furthermore, because meaning is such a broad topic, taking a theoretical perspective is necessary for understanding the multitude of ideas, definitions, and data available. In the field of counseling psychology, theoretical assumptions are tested empirically to provide evidence for their use in clinical practice. Empirical investigation of meaning is limited by inconsistent terminology, which makes summarizing the literature difficult (White, 2004). Park

and Folkman (1997), however, provide a comprehensive approach to describing meaning and meaning-making processes.

The authors built upon a model of coping formulated by Lazarus and Folkman (1984), which distinguished between problem-focused coping and emotion-focused coping. Park and Folkman (1997) further expanded this model by adding meaning-based coping. The authors suggest meaning-based coping consists of global and situation-specific meaning. Global meaning can be defined as “people’s basic goals and fundamental assumptions, beliefs, and expectations about the world” (p. 116). This definition is akin to the definition of existential meaning. Situational meaning, conversely, “refers to the interaction of a person’s global beliefs and goals and the circumstances of a particular person-environment transaction” (p. 121). Park and Folkman (1997) believe that both global and situational meanings are implemented when a person is faced with a challenging event and are forced to re-appraise that event.

According to the authors, this re-appraisal begins on a situational basis and moves toward the global basis (Park & Folkman, 1997). The challenging event leads from an appraisal of the situation, to an appraisal of the situational meaning, and then an attempt is made to align situational meaning with global meaning. Hence, the goal of meaning-making coping is to develop a congruency between situational and global meaning. Changing situational meaning to become more consistent with global meaning has been termed in the literature as *assimilation* whereas changing global meaning has been termed *accommodation* (Joseph & Linley, 2005; Parkes, 2001). The result of assimilation precipitates acceptance of the challenging event and accommodation can lead to the made meaning of posttraumatic growth, discussed later in this section (Joseph & Lindley, 2005). If the person is unsuccessful, however, in the assimilation between situational and global meaning, the person may experience negative symptoms such as

anxiety and rumination and continue to repeat coping mechanisms that do not necessarily relieve these symptoms. The intercorrelation between coping and meaning-making on both situational and global levels directs the psychological outcome of the challenging event. Park and Folkman (1997) created a model that indicates meaning propels coping and, therefore, meaning is to be regarded as essential in coping with a challenging life event such as a cancer diagnosis. Further research on meaning-based coping is scarce; however, in 2010 Crystal Park published a major review of the existing literature on meaning-making and its effect on the psychological outcome of challenging life events.

In her review, Park (2010) provided an integrated and complex picture of meaning and meaning-making (see Appendix S). This review also included a revamped illustration of the meaning-making model created by Park and Folkman (1997). The model distinguishes between situational and global meaning as well as the processes that occur in meaning-making efforts and meaning made. The model begins with a potentially stressful situation and concludes by indicating the recovery from this stressful event involves the reduction in the discrepancy created between its appraised meaning and global beliefs (Joseph & Linley, 2005). The processes to reduce the discrepancy are referred to as *meaning-making* processes.

Quantitative Studies on Meaning-making

Multiple studies have reported that meaning-making processes and the attempts that result in meaning made are correlated with better adjustment (Bower, Kemeny, Taylor, & Fahey 1998; Tolstikova, Fleming, Chartier, 2005; Westling, Garcia, & Mann, 2007). Bower et al. (1998) found meaning made during bereavement was related to less rapid declines in CD4 T cell levels and, therefore, better physical health among men with HIV. As an extension of that study, Westling, Garcia, and Mann (2007) found women with HIV who engaged in meaning-making

processes were more likely to experience posttraumatic growth and increase engagement in medication adherence. In regard to long-term cancer survivors, the meaning made of the illness has been found to be correlated with better adjustment (Fife, 1995; Park et al., 2008). It is important to note the process of meaning-making occurs over time in a dynamic manner; however, most of the studies in the existing literature focus only on a few retrospective time periods (Mancini & Bonanno, 2008).

Park (2010) reviewed the existing literature and found a significant gap between meaning-making theories and empirical studies testing them. Through this she highlighted the need for careful conceptualization of meaning and meaning-making processes. While the meaning-making model, founded upon existential and crisis theories, is largely accepted among researchers and clinicians, empirical support is lacking largely due to their abstract and complex ideas. The constructs of meaning and meaning-making, therefore, need to be operationally defined to produce empirical studies that test these theories.

Regardless of the limitations on measuring meaning, researchers have produced empirical data noting a positive relationship between a high level of perceived existential meaning and higher psychological wellbeing (Reker & Chamberlain, 2000). Schoen and Nicholas (2005) examined the relationship between existential meaning and illness in a sample of breast cancer patients. Results indicated women with higher levels of perceived existential meaning reported better quality of life when compared to a control group. Emotional, social, and functional wellbeing were also highly correlated with their level of existential meaning.

Multiple other studies have found existential meaning to be an essential ingredient in overall psychological wellbeing, successful transitions throughout life, and in making effort to prevent illness (Fife, 1995; Reker, Peacock & Wong, 1987; Shek, 1992). One such study

conducted by Vehling et al. (2011) focused on global meaning's role in predicting depression, anxiety, and demoralization in cancer patients. The results indicated global meaning and meaning-related life attitudes were both significant predictors of psychological wellbeing. Other studies have found lack of perceived meaning in life to be associated with higher levels of depression and suicidal ideation (Harlow, Newcomb, & Bentler, 1986; Wong, 1998). On the other hand, adult childhood cancer survivors may perceive life as meaningful, a perception that can potentially reduce depressive symptoms and lead to posttraumatic growth (Vehling et al., 2011). Pelusi (1997) also suggested that perceived meaning in life could be positively affected by the cancer experience. Overall, successfully adapting and growing from a traumatic experience or crisis situation can increase perceived meaning in life (Wong & Fry, 1998). In addition to quantitative studies, multiple qualitative studies have focused on existential meaning and cancer.

Qualitative Studies on Meaning-making

Qualitative accounts of existential meaning and illness have indicated that cancer patients frequently described existential meaning as having an impact on their experience of the illness (Coward, 2000; Moadel et al., 1999; Park & Folkman, 1997). Participants in qualitative studies largely described a feeling of having “made sense” of their illness. For example, Davis et al. (1998) noted a participant stating, “It makes sense, but I hate it. I don’t understand why cancer has to be, but it just is” (pg. 561). Mast (1996) indicated participants who reported their own cognitive appraisal of existential meaning had lower levels of distress in comparison to those who did not appraise their diagnosis. In a general sense, Vickberg et al. (2000) provided results that validate including existential meaning in models of illness.

Vickberg et al. (2000, 2001) provided further support for the role of existential meaning in enhancing psychological wellbeing. In 2000, the authors conducted a study regarding psychological distress in leukemia patients after receiving a bone marrow transplant. Results revealed global meaning was significantly negatively correlated with overall distress. In the second study in 2001, Vickberg et al. investigated how the level of global meaning moderated the effect of intrusive thoughts on psychological wellbeing after controlling for income level and marital status. The results of this study suggested that in a group of participants who endorsed low meaning, intrusive thoughts were positively correlated with distress. Both studies used the Life Attitude Profile—Revised (LAP-R; Reker, 1992) to assess the level of existential meaning in the participants. Regrettably, both of these studies had relatively small samples and are subject to the difficulties of defining the abstract construct of existential meaning. Despite the challenges of empirically investigating meaning/meaning-making, clinicians have begun targeting these constructs as interventions in clinical trials.

One such clinical trial found that breast cancer survivors who received a meaning-making intervention reported significantly higher levels of optimism, self-efficacy, and self-esteem when compared to the control group (Lee, Cohen, Edgar, Laizner, & Gagnon, 2006). Aside from clinical trials regarding meaning-making, multiple current psychotherapies facilitate meaning-making interventions including existential and narrative therapies. While psychotherapies often assume the search for meaning is adaptive, little research evidence exists to support this notion.

The *presence* of meaning is adaptive, yet the *search* for meaning is linked with experiences of increased distress and more negative changes (Linley & Joseph, 2011). The existing research indicates the search for meaning is associated with more symptoms of depression and higher reports of neuroticism (Steger, Frazier, Oishi, & Kaler, 2004; Steger,

Kashdan, Sullivan, & Lorentz, 2008). Joseph and Linley (2005, 2008) built on the writings of Yalom (1980) and Janoff-Bulman (1992) and stated that traumatic events shatter a person's assumptions about the self and the world, which propels that person to search for new meanings in life. The authors further stated that as meaning is created or found, the person reconstructs their worldview and new assumptions unfold.

Overall, the process of meaning-making can be considered vital for creating positive change in adjusting to a stressful life event, despite the challenges the search for meaning requires. Little research, however, has investigated meaning-making processes and if they lead to actual meanings made from stressful and/or traumatic events. The exception to this is the amount of research available regarding meaning-making and its impact on the development of posttraumatic growth (Armeli, Gunthert, & Cohen, 2001; Frazier, Tashiro, Berman, Steger, & Long, 2004; Sears, Stanton, & Danoff-Burg, 2003).

Posttraumatic Growth

Examples of finding meaning, growth, and positive change after traumatic events take root in ancient texts and philosophies from the Greek tragedies to Buddhist beliefs to the popular wisdom of German philosopher Nietzsche. Nietzsche once stated, "Was mich nicht umbringt mact mich starker" or "What does not kill me makes me stronger". This quote is the underlying premise of posttraumatic growth. Though the idea of posttraumatic growth has been present for hundreds of years, and more recently discussed by existential psychologists and philosophers (Frankl, 1961; Fromm, 1941; Horney, 1950; Kierkegaard, 1884; May 1977; Yalom, 1980), it has not been the focus of empirical attention until the last twenty years (Calhoun & Tedeschi, 2006; Ickovics & Park, 1998; O'Leary & Ickovics, 1995; Park & Helgeson, 2006; Park, Lechner, Antoni, & Stanton, 2009; Tedeschi & Calhoun, 1995, 2004, 2005; Tedeschi, Park, & Calhoun,

1998b). Multiple definitions, however, need to be considered to develop a clear understanding of posttraumatic growth.

The Process of Posttraumatic Growth

Calhoun and Tedeschi (1999) defined posttraumatic growth (PTG) as “a positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (p. 11). The authors further explained PTG as characterized by an increased appreciation for life, meaningful interpersonal relationships, increased sense of strength, a change in priorities, and a deeper sense of existential meaning. Tedeschi and Calhoun (2004) proposed a model of posttraumatic growth (see Appendix T). This model proposes a process that includes individual characteristics, self-disclosure and social support, and significant cognitive processing of the traumatic event. The culmination of this process results in a life narrative that is developmental and continuous in nature (Tedeschi and Calhoun, 2004). In this model, ‘deliberate rumination’ is akin to the meaning-making processes described by Park (2010). Tedeschi and Calhoun also noted that the presence of posttraumatic growth does not indicate a lessened degree of psychosocial distress. In fact, some degree of psychological distress is necessary to not only set the process in motion, but some enduring discomfort may enhance and maintain the experience of posttraumatic growth.

Aside from Tedeschi and Calhoun’s seminal work in this area, in the broader literature PTG has been labeled using different terms including the following: thriving (O’Leary, Alday, & Ickovics, 1998; O’Leary & Ickovics, 1995), benefit finding from adversity (Affleck & Tennen, 1996), adversarial growth (Linley & Joseph, 2004), and stress related growth (Park, 1999). It is important, however, to distinguish PTG from resiliency, which can be defined as a person returning to his or her typical lifestyle without dramatic positive psychological changes

(Bonanno, 2004). Resiliency lacks the process of finding, ascribing, and cognitively engaging in a meaning-making process. PTG, on the other hand, includes a meaning-making process, as described above.

Duran (2013) also describes the PTG as process of understanding the traumatic event, what caused it, and the meaning we ascribe to it. In most circumstances, people attach negative meaning to the traumatic event and find the appraised meaning to be incompatible with global worldviews (Baumeister, 1991; Park, 2005a, 2005b, 2010). In reaction to the violation of worldviews, individuals may develop a sense of meaninglessness (Park & Folkman, 1997). Therefore, cognitively engaging with the existential challenge to find meaning for the traumatic event may occur (Park, 2010). Such cognitive engagement might include asking existential questions like, “Why me?” or “Why my child?” (Miles & Crandall, 1983, p. 20).

Research on traumatic events largely has focused on the negative sequelae of the experience and, subsequently, the methods of treatment for posttraumatic stress disorder and other related psychopathologies (Meyerson, 2011). In the childhood cancer literature, most of the research is based on biomedical models of disease and deficits in coping. Unfortunately, this literature has defined the disease as a burden and has pathologized patients and families as unable to recognize their strengths and resources (Parry & Chesler, 2005; Walks, 2006). In more recent years, however, research has shifted from studying the negative outcomes to resilience and posttraumatic growth in the face of adversity. Emerging research on PTG suggests the traditional deficit oriented approach to life threatening illnesses, such as cancer, overlooks the positive psychological changes and transformations such as growth, wisdom, self-knowledge and awareness, and the purpose and meaning of life (Ickovics & Park, 1998; McMillen, 1999; Paterson, Thorne, Crawford, & Tarko, 1999; Siegel & Schrimshaw, 2000; Tedeschi & Calhoun,

1995; Walsh, 1995, 2006; Wolin & Wolin, 1993). This shift has a new goal of discovering and uncovering pathways to adjustment and developing effective interventions to facilitate adjustment and growth (Tedeschi & Calhoun, 2004).

Who Experiences Posttraumatic Growth?

Recent research regarding PTG outcomes has been conducted across numerous populations. Significant numbers of participants have reported PTG after a multitude of traumatic events, including the death of a child, the death of a spouse or parent, car accidents, divorce, breast cancer, terminal illness, military combat, sexual assault, natural disasters, bereavement, and brain injury (Bellizzi & Blank, 2006; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Helgeson, Reynolds, & Tomich, 2006; Joseph & Linley, 2004; Manne et al., 2004; Mosher, Danoff-Burg, & Brunker, 2006). Relevant to this study, emerging research on PTG suggests the traditional deficit oriented approach to life threatening illnesses, such as cancer, overlooks the positive psychological changes and transformations such as growth, wisdom, self-knowledge and awareness, and the purpose and meaning of life (Ickovics & Park, 1998; McMillen, 1999; Paterson, Thorne, Crawford, & Tarko, 1999; Siegel & Schrimshaw, 2000; Tedeschi & Calhoun, 1995; Walsh, 1995; Wolin & Wolin, 1993). The emerging literature also suggests people report PTG in three domains included change in relationships, change in sense of self, and change in life philosophy (Tedeschi & Calhoun, 1999). We must keep in mind, however, that PTG is not universal and not all people who experience a traumatic event report PTG. In fact, the available data states that between 30% and 90% of people who face adversity via a serious personal crisis experience some positive change (Tedeschi & Calhoun, 2005). The literature has also shed some light on some factors that may or may not lead to experiencing PTG.

Linley and Joseph (2004) evaluated the available evidence on who is more likely to experience PTG. The authors stated several personality factors including self-efficacy, openness to experience, conscientiousness, extraversion, and agreeableness have been positively associated with experiencing PTG. These traits could predispose a person to experience PTG after a traumatic experience. Additionally, the impact of demographic variables on the development of PTG has been examined. SES has not been found to have a significant impact on the development of PTG (Barakat, Alderfer, & Kazak, 2006; Currier, Holland, & Neimeyer, 2009; Phipps, 2007). Additionally, research has not indicated gender as having a significant impact on the development of PTG (Alisic, van der Schoot, van Ginkel, & Kleber, 2008; Cryder, Kilmer, Tedeschi, & Calhoun, 2006; Currier et al., 2009; Hafstad, 2011; Kilmer et al., 2009; Milam, Ritt-Olson, & Unger, 2004; Phipps et al., 2007). Research on other variables such as age, education level, and marital status has produced contradictory results.

With respect to age, Pietrzak et al. (2010) conducted a study measuring PTG in veterans of war and found that younger veterans were more likely to experience PTG after a war experience. In a review of the literature, Linley and Joseph (2004) also found younger participants were more likely to report experiencing PTG. Grubaugh and Resnick's (2007) study examining victims of assault contradicted this evidence finding instead that older individuals were more likely to develop PTG. In regard to education level, this study also indicated less educated individuals were more likely to develop PTG. In a sample of breast cancer patients, those who were married, employed, or both also have demonstrated higher levels of PTG (Bellizzi & Blank, 2006).

More generally speaking, studies conducted regarding PTG have produced mixed results. Some studies have found higher levels of PTG were associated with lower levels of

psychological distress (Park, Cohen, & Murch, 1996; Frazier, Conlon, & Glaser, 2001), while other empirical evidence suggests no significant relationship between the two (Cordova et al., 2001; Powell et al., 2003). Specifically, Cordova et al. (2001) matched a group of breast cancer survivors with a healthy control group and found that while cancer survivors reported higher levels of posttraumatic growth, there was no significant difference in levels of depressive symptoms when compared to the control group. Notably, most of the research conducted on PTG as a response to adversity has been focused on adult populations. Recently, however, Meyerson (2011) and Duran (2013) reviewed the available research on the PTG progress among children and adolescents.

Children and Adolescents' Experiences of Posttraumatic Growth

Meyerson (2011) conducted a general review of PTG in children and adolescents that included 25 studies examining associations between PTG and variables associated with PTG in adults. The author hypothesized that young people would have similar experiences when compared to adults and hypothesized a model of PTG for youth (see Figure 2). The results of this review found preliminary support for links between psychological, social, environmental, and demographic predictors of PTG in youth, which is similar to the research on adults. One unique trajectory of PTG in children is that it may decay more quickly over time in comparison to PTG in adults. Results also suggest that PTG experiences may be optimal during adolescence and early adulthood and when the severity of the trauma and posttraumatic stress are moderate (Meyerson, 2011).

As the first systematic review of the available literature on PTG in children and adolescents, Meyerson's (2011) review has some significant limitations. Specifically, a significant portion of the studies (20%) used measures that were not originally intended to assess

PTG and nearly all of the measures used were not designed for use with children. Further, the study cannot demonstrate any correlations between certain variables and PTG due to the lack of non-trauma comparison groups. In regard to this study on childhood cancer survival, most of the studies in the Meyerson (2011) review focused on PTG in children who experienced group related traumas, such as natural disasters in the form of earthquakes and hurricanes and less on the traumatic experience of childhood cancer. Duran's (2013) review focuses specifically on the available literature on PTG in childhood cancer survivors.

Duran's (2013) review is a narrative synthesis of the existing literature in regard to the positive effects perceived by childhood cancer survivors and their families. This investigation included 20 quantitative, 12 qualitative, and 3 mixed methods studies, for a total sample of 2087 childhood cancer survivors. The specific allocation of participants for each type of study (i.e. quantitative, qualitative, mixed), was not expanded upon in the methods of the study. The author identified five themes of PTG in this population including 1) meaning-making, 2) appreciation of life, 3) self-awareness, 4) closeness of family togetherness, and 5) a desire to pay back society. Parry and Chesler's (2005) qualitative study included in this review noted childhood cancer survivors reporting the development of new values and priorities. For example, one participant stated, "Even though it [cancer] was really bad, I learned a lot... what's important in life. Like money is not important. I just want to be happy, have someone love me" (p. 1063) and another reported, "I have a greater capacity to empathize with others... I don't necessarily look at someone and see 'different' anymore. Because I know how that felt" (p. 1062).

Overall, the outcome of the Duran (2013) synthesis suggests that most children and adolescents who survive childhood cancer do not only recover but also surpass their previous psychological and social functioning. Cognitively engaging in the meaning-making process of

having their beliefs (global meaning) shattered, working through their illness, making meaning of the illness (situational meaning), and reevaluating meaning in life leads childhood cancer survivors to experience PTG. This narrative synthesis, however, is not without limitations including a limited number of studies to analyze. With the limited number of studies available, the author decided to include each quantitative and qualitative studies available that reported at least one positive outcome of childhood cancer, regardless of their weaknesses. Despite the limitations of Duran's (2013) review, the results have the potential to inform counselors and psychologists about the experience of PTG in childhood cancer survivors. This information on PTG in this population could facilitate the development and implementation of interventions to enhance quality of life in childhood cancer survivors.

Facilitating Posttraumatic Growth in Counseling

PTG can be facilitated in therapy (Moran, Burkner, & Schmidt, 2012). It is important to note, however, that the general paradigm for treating survivors of trauma has been dominated by the medical model and focuses very clearly on the removal of psychopathological symptoms. In fact, most clinicians appropriately see the goal of therapy as the reduction of subjective distress in their clients. In regard to PTG, however, it is important for clinicians to consider the necessary coexistence of subjective pain and growth that may be necessary for PTG to be more likely (Tedeschi & Calhoun, 1999; Yalom & Lieberman, 1991). As therapists, we should also bear in mind that it is clearly necessary to assist the childhood cancer survivor to manage the strong and sometimes overwhelming emotions that may arise in working toward PTG.

Significant research has found a link between the symptoms of posttraumatic stress and PTG (Alisic, van der Schoot, van Ginkel, & Kleber, 2008; Kilmer et al., 2009; Salter & Stallard, 2004) and these results are consistent with PTG and meaning-making models (Park & Folkman,

1997; Tedeschi & Calhoun, 2007). Specifically, clinicians should understand that traumatic events produce fundamental changes in self-understanding via two pathways: the change of answers to “who am I” and “what is my life story” (Tedeschi & Calhoun, 1997). For most people who have suffered and survived a trauma, their life views change as their life story is bisected by the event into life before and life after “it”. In order to facilitate posttraumatic growth, clinicians could help their clients answer the above questions. No specific therapies have developed a focus on facilitating PTG, however, three key elements of facilitating PTG include: 1) developing positive coping and rumination styles, 2) schema and narrative change, and 3) social support and the therapeutic alliance (Moran, Burkner, & Schmidt, 2012). Specific interventions of mindfulness to identify coping and rumination styles, cognitive interventions to challenge maladaptive and dysfunctional beliefs associated with the coping styles, narrative journaling or oration, and social support via family interventions and the “here and now” of the therapeutic relationship are several methods to facilitate the development and the maintenance of PTG in childhood cancer survivors.

Qualitative Research Methods

Qualitative research procedures “stand in stark contrast to the methods of quantitative research” (Creswell, 2003, p. 179). Further, qualitative researchers utilize a wide array of methods in order to gain a deeper understanding of the subject matter they are exploring and each qualitative method makes the world visible in a different way. Therefore, there is “frequently a commitment to using more than one interpretive practice in any study” (Denzin & Lincoln, 2004, p. 3-4). Qualitative methods are used in a wide variety of areas, including health care, social justice, and education. This method of research is constantly growing and evolving while simultaneously challenging the border between research and art by studying “things in

their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 2005, p. 3). Qualitative research offers an idiographic understanding of the sample being studied (Bryman, 1988) and it helps decipher complex biopsychosocial phenomena and therefore, affords new possibilities for informing clinical practice (Boyle, 1991). It is important to note, however, that qualitative research has only become accepted as a method of research within the health disciplines within the last 20 years (Henwood & Pidgeon, 1992; Smith 1996a, 1996b; Turpin et al., 1997).

Part of the overall qualitative research methodology includes acknowledging the researcher as being subjective and biased (Chang, 2008; Ellis, 2004) and is an accepted practice from multiple theoretical perspectives (Denzin, 1994; Lather, 1991; MacNaughton, 2001). In order to address the inherent bias found in qualitative research, methods such as reflective journaling are employed to provide the researchers with deep understanding of his or her experiences in the study. It is unnecessary, however, to remove or control the researchers’ bias, but rather acknowledge it. The researchers play such a significant part in the process and instead of diminishing this role IPA and reflective journaling explores and acknowledges the researchers role.

Instead of attempting to control researcher values and biases through specific methodology, the role of journaling aims to acknowledge those values and biases. In reflective journaling, the researchers have the ability to reflect on and consider the dynamics between themselves and the data (Finlay & Gough, 2003; Hutchinson & Wilson, 1994; Merrick, 1999; Nicolson, 2003). This can facilitate reflexivity (Ortlipp, 2008). Specifically, it makes clear “how the researcher’s own experiences, values, and positions of privilege in carious hierarches have influenced their research interests, the way the choose to do their research and the ways they

choose to represent their research findings” (Harrison, MacGibbon, & Morton, 2001, p. 325).

Reflective journaling will also allow the reader to “assess how and to what extent the researcher’s interests, positions, and assumptions influenced inquiry” (Charmaz, 2006, p. 188).

Further, reflective journaling enhances the researchers’ self-awareness during the implementation of the study and “aids in making visible practice and construction of knowledge within research in order to produce more accurate analyses of our research” (Pillow, 2003, p. 178). This project will use reflective journaling to foster reflexivity about the researchers’ interpretations of the photographic and interview data.

Photovoice as a Qualitative Research Methodology

Overview. Sontag (1977) has described a photographer as the following:

An acute but non-interfering observer - a scribe, not a poet. But as people quickly discovered that nobody takes the same picture of the same thing, the supposition that cameras furnish an impersonal, objective image yielded to the fact that photographs are evidences not only of what's there but of what an individual sees, not just a record but an evaluation of the world (p. 88).

Previously known as photo novella, photovoice is a methodology that may expand upon Sontag’s idea of how photography can enrich our understanding of human experience and evaluate the world from a childhood cancer survivor’s perspective. Photovoice is a qualitative methodology in which participants purposefully document, through photographs, various elements of their lives and experiences. The photovoice methodology involves giving cameras to participants with the intention of using photography to identify, represent, and enhance their communities (Wang & Burris, 1997). This method will be used to collect data and data analysis will follow this method’s coding framework (Wang & Burris, 1997).

Historical and Theoretical Background. From the field of public health, the developers of this methodology, Wang and Burris (1997) describe photovoice as a data collection process in which participants can identify and represent the community through photography as they act as recorders and potential catalysts for change. This method was originally developed to influence policy and create change to benefit marginalized communities. Three main sources influenced how photovoice was developed: 1) theoretical literature from educational perspectives, feminist theory, and documentary photography; 2) efforts of photographers and educators to challenge assumptions; and 3) the authors' experience articulating and applying the process (Wang & Burris, 1997).

While the original intention of this methodology was to create grassroots movements to improve local communities, it is adaptable to collecting data for general public health issues, such as cancer. With photovoice, different stories are told, different photographs are captured, and different outcomes are pursued. Despite the diversity of photovoice projects, each project has the potential to reveal the rich experiences of the project's participants and empowers them to share these experiences.

Wang (1999) suggested a structured technique for selecting photos and guiding dialogue known as "SHOWeD" (What do we See here? What is Happening here? How does this relate to Our lives? Why does this situation, concern, or strength Exist? What can we Do about it?), however, this approach to interpreting and analyzing the content of the photographs has not always been successful. Another researcher, McIntyre (2003), identified SHOWeD to be constricting and to limit personal interpretation. Therefore, this study will utilize a less structured technique and encourage participants to discuss why their photographs are significant

and rely on instinct when choosing their photographs for discussion and respond to more personal questions (McIntyre, 2003).

Photovoice Literature.

Weber (2008) discussed photographs to be valuable to research in that they have the ability to transmit multiple messages, pose questions, and point to both abstract and concrete thoughts of participants. Weber makes a case for using photographs in research as they capture the indescribable, hard-to-put-into-words aspects of knowledge that might otherwise not be discussed. Photographs elicit emotional and intellectual responses (Weber, 2008) and seize “the fullness of lived experiences by describing, interpreting, creating, reconstructing, and revealing meaning” (Watrin, 1999, p. 93). This study uses photographs as data, to make connections between research and lived experience (Garoian, 1999). Photographs have been used as data in anthropological and psychological research.

The field of anthropology has extensively used photography as a research method throughout its rich history as a social science (Collier & Collier, 1986). The field of psychology, however, has also developed a research method, termed auto-photography, to measure self-concept (Combs & Ziller, 1977; Dinklage & Ziller, 1989; Ziller & Rorer, 1985). Using auto-photography, researchers ask participants to take photographs in response to prompts and discuss his or her photos in interviews. Authors have described auto-photography as producing photographs that answer open ended questions about self-concept in a nonverbal manner and possessing a “rich revealingness” about the presentation of self (Combs & Ziller, 1977, pg. 452). Using photographs as data has the potential to offer a rich description of childhood cancer survivors experience with meaning and posttraumatic growth. Specifically, this study will use a method known as photovoice.

Wang and Burris (1997) first used photovoice in their seminal study with women in rural China. In this study the authors explored the health status of Chinese village women and allowed the participants to communicate their burdens and needs to political officials. The participants created photographs that depicted the dangers of leaving children alone at home, poor hygienic conditions, and lack of opportunity for education. Since this seminal article was published photovoice has been growing in popularity and has been used to gain a better understanding of the experiences of homeless people (Radley, Hodgetts, & Cullen, 2005), senior citizens (LeClerc, Wells, Craig, & Wilson, 2002), rural Chinese women (Wang & Burris, 1997), immigrant workers (Gallo, 2002), mothers with learning disabilities (Booth & Booth, 2003), refugee youths (Berman, Ford-Bilboe, Moutrey, & Cekic, 2001), and people living with HIV/AIDS (Hergenrather, Rhodes, & Clark, 2006).

Lal, Jarus, and Suto (2012) conducted a review of the existing literature, which utilized the photovoice method. This review found 191 original studies using the photovoice method and approximately 24% of these explored the experiences of individuals with a specific illness and/or disability. Additionally, a review in the public health literature revealed while photovoice methods are rooted in Wang's original methodology, most studies alter photovoice procedures to meet the needs and constraints of the researcher's individual project (Catalani & Minkler, 2009). Photovoice's methodology lends itself well to adaptation. This study adapts Wang's original methods to include Interpretive Phenomenological Analysis to deepen the understanding and meaning of the data.

Interpretive Phenomenological Analysis for Qualitative Data

Smith's (1996) seminal article introduced IPA into psychological literature. IPA is built on phenomenology, which originated with hermeneutics (the theory of interpretation), and

symbolic-interactionism. Symbolic interactionism posits that the meanings an individual ascribes to an event are central to the concern; however, this meaning is only accessible via a process of interpretation. Specifically, IPA explores *how* people ascribe meaning to their experiences in their interactions with the environment (Smith, Jarman, & Osborn, 1999).

IPA is a methodology committed to exploring how people make sense of major and meaningful life experiences. While “experience” is an intricate concept, IPA’s goal is oriented toward “what happens when the everyday flow of lived experiences takes on a particular significance for people” (Smith, Flowers, & Larkin, 2009, p. 3). In this qualitative analysis, the research participant describes how he or she makes sense of the experience or event, and the IPA researcher engages in interpretation of his or her account. Smith, Flowers, and Larkin describe the researcher as being:

engaged in a double hermeneutic because the researcher is trying to make sense of the participant trying to make sense of what is happening to them. This captures the dual role of the researcher. He/ she is employing the same mental and personal skills and capacities as the participant, with whom he/ she shares a fundamental property – that of being a human being. At the same time, the researcher employs those skills more self-consciously and systematically. As such, the researcher’s sense-making is second order; he/ she only has access to the participant’s experience through the participant’s own account of it. (p. 3-4)

IPA data is most commonly collected via semi-structured interviews. Transcripts of the interviews are then analyzed individually via a systematic, qualitative analysis. This analysis is, in turn, presented as a narrative account with the researcher’s detailed, analytic interpretation is presented and supported with verbatim excerpts from the participants.

Overall, IPA is distinct from other forms of qualitative research in that it uses a combination of psychological, idiographic, and interpretive components to gain an understanding of how participants make sense of their personal and social world via detailed examination of

their life, world, personal experiences, and personal perceptions about an event (Smith & Osborn, 2007).

IPA is a cyclical process and moves through the following stages:

- Stage 1: First encounter with the text and associated photographs.
- Stage 2: Preliminary themes identified
- Stage 3: Grouping themes together as clusters
- Stage 4: Tabulating themes in a summary table

Stage 1. The researcher reads the transcript a number of times to become as familiar as possible with each participant's individual experiences. Each reading gives the researcher another chance to develop new insight (Smith & Osborn, 2008). During this first reading, the researchers use the left-hand margin to annotate what he or she finds interesting and/or significant about the participant's response in the interview text.

Stage 2. In this stage, the researcher returns to the beginning of the transcript and uses the right-hand margin of the interview transcript and the right-hand side of the back of the photograph to document emerging theme titles (Smith & Osborn, 2008). This process involves transforming the initial notes in to more concise phrases that may include more psychological terminology. This is continued through the whole transcript and with all of the photographs the participant selected for inclusion in the data. Overall, this stage transforms the initial impressions and notes into themes.

Stage 3. The emergent themes are chronologically listed. When this list is compiled, the researchers will begin to look for connections between them. These connections are clustered together and superordinate concepts may also emerge. These themes will reflect the participants' original words and thoughts as well as the researchers' interpretations.

Stage 4. The researcher will compile a coherently ordered table of the emergent themes. The clusters will be given names and represent the superordinate themes. The table will provide a summary of which themes go with each superordinate theme.

This process occurs with each transcript and the researcher can use the themes they identify in previous transcripts to help orient them to new transcripts. This may help the researcher to identify not only similarities, but also recognize the differences in each of the participant's experiences with surviving childhood cancer. The tables of themes will be constructed on not only the frequency of their occurrence in the data, but also on the richness of the passage that highlight the themes (Smith & Osborn, 2007). The overall aim of the research team will be to understand the content and the complexity of the meaning made by participants, rather than simply the frequency.

IPA is widely used in psychological research in Britain (Duncan, Hart, Scoular, & Brigg, 2001, Thompson, Kent, & Smith, 2002; Clare, 2003; Biggerstaff, 2003; French, Maissi, Marteau, 2005). In regard to specific populations, IPA has been used to explore the experiences of palliative patients (Muggleton, Guy, & Howard, 2014), adolescents with haematological malignancy (Al Omari & Wynaden, 2014), spinal cord injury patients (Nunnerley, Hay-Smith, & Dean, 2013), patients with lower extremity ulcers (Wellborn & Moceris, 2014), patients with osteoarthritis (Bukhave, la Cour, & Huniche, 2014), women with gestational diabetes (Carolan, 2013), and compulsive hoarding (Kellet, Greenhalgh, Beail, & Ridgway, 2010). This research method has been gaining momentum in psychological research in the United States. IPA is committed to exploring meaning and meaning-making and this links it quite closely with the purpose and photovoice methodology of this study. Specifically, Brundsen and Goatcher (2007)

suggest using interpretive phenomenological analysis (IPA) to supplement the coding done by the participants in the photovoice project.

Brunsden and Goatcher (2007) suggest, due to the characteristics of visual data, IPA's focus on hermeneutics and phenomenology makes it particularly suitable for analyzing photographs. One study has been conducted pairing photovoice methodology with IPA for visual and verbal data (Pickin, Brunsden, & Hill. 2011). This study explored the experience of foster parents and identified five super-ordinate themes including: angry frustration, promoting security and well-being, an ambiguous life, the impact of the children, and coping. The authors did not note any reflective methods to identify their values and biases and they did not discuss the limitations to the methodology and analysis. While the use of photovoice methodology and IPA seem to pair well together, no significant evidence or studies have outlined the strengths and limitations of such practices. This study will provide more detail and include the strengths and limitations of these combined methods for future research implications.

Definitions of Constructs

Park (2010) reviewed the existing literature and found a significant gap between meaning-making theories and empirical studies testing them. Through this she highlighted the need for careful conceptualization of meaning and meaning-making processes. While the meaning-making model, founded upon existential and crisis theories, is largely accepted among researchers and clinicians, empirical support is lacking largely due to their abstract and complex ideas. The constructs of this study are, therefore, operationally defined below.

Biopsychosocial stressors. Biopsychosocial stressors experienced by adult survivors of childhood cancer are defined in this study as “a particular relationship between the person and

the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, pg. 19).

Meaning-making. Meaning-making is the process of which survivors of trauma, in this study, survivors of childhood cancer, come to “see or understand the situation in a different way and review and reform one’s beliefs and goals in order to regain consistency among them” (Park & Ai, 2006, p. 393). Specifically, it is a process that involves efforts to understand the appraised meaning of a traumatic event and restore or incorporate that understanding into one’s global meaning system after that system has been disrupted (Park & Folkman, 1997).

Posttraumatic Growth. Calhoun and Tedeschi (1999) defined posttraumatic growth as “a positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (p.11). The authors further explained posttraumatic growth as being exhibited by an increased appreciation for life, meaningful interpersonal relationships, increased sense of strength, a change in priorities, and a deeper sense of existential meaning (Calhoun & Tedeschi, 2004).

Reflexivity. Defined as “the researcher’s scrutiny of his or her research experience, decisions, and interpretations in ways that bring the researchers into the process to allow the reader to assess how and to what extent the researcher’s interests, positions, and assumptions influenced inquiry” (Charmaz, 2006, p. 188). Additionally, it includes a component of self-awareness, which aids in making visible the practice and construction of knowledge within research in order to produce more accurate analyses of our research” (Pillow, 2003, p. 178).

Photovoice. Defined as “a process by which people can identify, represent, and enhance their community through a specific photographic technique. It entrusts cameras to the hands of people to enable them to act as recorders, and potential catalysts for change, in their own

communities. It uses the immediacy of the visual image to furnish evidence and to promote an effective, participatory means of sharing expertise and knowledge” (Wang & Burris, 1997, p. 369).

Interpretive Phenomenological Analysis. Defined as a “meaning-focused, qualitative method, which is committed to understanding the first-person perspective from the third-person position, so far as is possible, through intersubjective inquiry and analysis” and “offers an established, systematic, and phenomenologically-focused approach to the interpretation of first-person accounts, which is committed to situating personal meaning in context” (IPA; Smith, 1996, p. 9).

Summary

The survival rates from childhood cancers are increasing. As the population of young adult childhood cancer survivors gets larger, the field grows more concerned with the implications of their cancer experience and treatment on psychological wellbeing. Most of the research on young adult childhood cancer survivors has focused on how this population has been affected by the physiological medical treatments used to biologically cure cancer. The focus on biological cure has left psychological late effects largely neglected. The available research suggests that a significant portion of adult childhood cancer survivors experience intrusive, avoidant, and arousal symptoms of posttraumatic stress, depression, and suicidal ideation. The available research also suggests, however, the majority of adult childhood cancer survivors are relatively well adjusted and experience posttraumatic growth. Existential meaning has been theorized by Frankl (1963), May, Angel, and Ellenberger (1958), and Yalom (1980) as being important factor in understanding human suffering and illness.

As scientist practitioners in the field of counseling psychology, theory drives our research. Existential and crisis theories emphasize the importance of meaning-making in understanding posttraumatic growth after facing the adversity of cancer diagnosis and treatment. Each theory bolsters the support for exploring the meaning-making process and how it could result in posttraumatic growth after surviving childhood cancer. Empirical investigation of meaning is limited by inconsistent terminology, which makes summarizing the literature difficult (White, 2004). Park and Folkman (1997), however, provide a comprehensive approach to describing meaning and meaning-making processes and Park (2010) provided an integrated and complex picture of meaning and meaning-making. The meaning-making process has found the *presence* of meaning is adaptive, yet the *search* for meaning is linked with experiences of increased distress and more negative changes (Joseph & Linley, 2011). The empirical literature has evolved from the meaning-making process outlined here is an integral part of the process of posttraumatic growth. PTG is characterized by an increased appreciation for life, meaningful interpersonal relationships, increased sense of strength, a change in priorities, and a deeper sense of existential meaning.

Given the above literature, this study is meant to address the lack of literature on adult survivors of childhood cancer and their experiences post treatment. Additionally, this research has the potential to make salient the importance of promoting the best long-term possibilities for childhood cancer survivors. The results could increase awareness of the unique experience of surviving childhood cancer within the field of counseling psychology. Given the gaps noted above, this study seeks to answer the following question: 1) What is it like to be a survivor of childhood cancer?

Additionally, the existing *empirical* literature has not matched the depth, richness and complexity of that described in the existential/trauma *theoretical* literature in their explanations of meaning and meaning-making. The abstract and metaphoric nature of these constructs (meaning-making and PTG) call for more creative methodologies to capture the breadth and depth of their complexities (Park, 2010). This study heeds that call via a methodology known as photovoice. Photovoice designed to make meaning of how stories of coloring and crayons turned to stories of chemotherapy, and the growing up of those childhood cancer survivors. IPA will further aid in the understanding of the experiences of this population.

Compensation: \$25



If so, you are eligible to participate in a research study using photography to tell your story to a researcher hoping to learn more about childhood cancer survival into adulthood. The study will take approximately 3-5 hours of your time, over two meetings with the researcher. Contact her at the email below for more information.



Childhood Cancer Study
Contact Erin L. Sadler, M.A.
ELSADLER@BSU.EDU

Appendix C

Email & Social Media Recruitment Letter

You are invited to participate in a dissertation study of childhood cancer survivors. Those individuals who are eligible for this study are both male and female childhood cancer survivors between the ages of 18-35, who were treated between ages 10-17, and have been off treatment for at least three years.

The purpose of this study is to understand the needs and aspirations of adult childhood cancer survivors, using the arts-based research method called photovoice. According to Caroline Wang and Mary Ann Burris, photovoice is a process by which people can identify, represent, and enhance their community through photography. Photovoice uses visual image and accompanying stories to provide a voice and to promote an effective way of sharing individuals' experience and expertise. The use of photovoice in this study is to enable childhood cancer survivors to photograph their lives as a way of documenting their perspectives, strengths, and struggles.

You will be compensated for your participation in the study. Each participant will receive \$25 OR a \$25 donation will be made to an area children's hospital.

If you are interested in participating, please email the principal investigator at elsadler@bsu.edu.

Sincerely,
Erin L. Sadler, MA
Principal Investigator
Ball State University
Dept. of Counseling Psychology
Elsadler@bsu.

Donald R. Nicholas, Ph.D., HSPP
Faculty Advisor
Ball State University
Dept. of Counseling Psychology
dnichola@bsu.edu

Appendix D

Project Overview Letter

Dear Participant,

Thank you so much for being willing to participate in this study titled: *A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood*. As a part of this study, you are asked to respond to prompts through photography. Participation in this study will include taking approximately 27 photographs in response to these prompts provided in this packet. After you complete your roll of film on your own, you will return the disposable camera to the principal investigator in the prepaid USPS envelope, also found in this packet. Then you and the researcher will schedule the second meeting/interview, which will last for approximately 1.5-2 hours to discuss the photographs.

You may photograph individuals in public spaces (such as in a public park, on sidewalks) without their consent. If the person is identifiable, meaning you can easily see his or her face, please give the enclosed flyer so he or she may gain an understanding of the project and the reason you want to take his or her photograph. Also, have that photographed person sign the Media Release Form found in this packet. Return the signed Media Release Form to the principal investigator.

In the event you wish to photograph a person in a private space (such as homes, classrooms, inside vehicles, etc.), principal investigator must obtain written consent and media release forms. If this private space is an organization, the principal investigator must also obtain a letter of support before you take that person's photograph. Please do not take a person's photograph in a private space without contacting the principal investigator beforehand to obtain consent and media release. You may provide a potential person to photograph with the Contact Information Sheet found in this packet. They can fill out the form for you to then return to the principal investigator. She will then obtain consent from this person and inform you when you make take the photograph in a private space.

If you intend to take photos of minors (under 18 years of age) in private spaces, the principal investigator must also obtain consent from the minor and his or her legal guardians (parents). Please follow the same procedures as above with the child's legal guardian. The principal investigator will obtain the necessary consent and media release to allow you to take the child's photograph, if/when the parent allows you to do so.

Also included in this packet is a guide including tips and tricks for taking photographs.

If you should have any questions throughout the duration of the research project, please contact me, the principal investigator, at any time. I can be reached through phone or email. Email is preferable.

Thank you so much for your willingness to participate in this project!

Erin L. Sadler, Principal Investigator
Elsadler@bsu.edu
(765) 285-8058

Appendix E

Informed Consent for Participation in Research Study

Study Title: A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood

Study Purpose & Rationale: The purpose of the present study is to understand childhood cancer survivors' experiences with their illness. This study will assist mental health and medical professionals understand childhood cancer's effect on adult life. This study has the potential to influence policy makers in understanding the needs of childhood cancer patients and childhood cancer survivors, and, therefore, can influence the availability of resources to this population. This study will also add to the research literature available on childhood cancer survivors.

Inclusion/Exclusion Criteria: To be eligible to participate in this study, you must be between the ages of 18 and 35 and have been treated for childhood cancer between the ages of 10 and 17. Additionally, you must be disease free and off treatment for at least three years.

Participation Procedures & Duration: The methodology for this study is a form of participatory action research known as photovoice. For this study you will be asked to respond to prompts regarding your illness. You will then discuss these photos and engage in a two face-to-face interviews with the principal investigator. In the first interview, which will last approximately 1.5 hours, you will discuss the research study and be provided with a camera and the prompts. You will be provided with a packet including a copy of this consent form and everything you need to complete the study. In the second interview, you will to discuss the photographs you have taken. The interview site will be at a location that is convenient to you. During the first meeting, you will sign an informed consent and photograph release forms. We will establish a timeline for completion of your participation at the first meeting. After the first meeting you will respond to the prompts and taken approximately 27 photos and return the camera via a USPS prepaid envelope to the researcher. The researcher will develop the film and the second meeting will be scheduled. At the second meeting, which will last approximately 1.5 to 2 hours, you will discuss your photographs with the researcher. This study will take place over a period of 3 to 6 months, depending on the timeline of all participants' completion times. At the end of the study, you will be invited to a community art exhibit of the photographs taken. Your participation in the exhibition is completely voluntary and you do not have to participate in the exhibition to participate in this study. The purpose of the exhibition is to reach policy makers and may be able to garner awareness and increase the availability of resources in the community for adult survivors of childhood cancer.

Data Confidentiality and Anonymity: All of the data obtained from the photographs and the interviews will be confidential. Your name will not appear in any publication, presentation, or exhibition of the data. It is important to note, however, that you may be identifiable via your photographs if you use any self-portraiture. If you choose to take a

photograph of another identifiable person, you are required to alert the principal investigator and provide her with this person's contact information in order to obtain his or her consent and release before you take the person's photograph. Additionally, some of your comments may be included in the reports written to summarize what has been learned from this study, however, the summary will not include any identifying information about you. Neither your name nor your identity will be used for any publication or publicity purposes without your written permission.

Audio Tapes: The interviews will be audio recorded for transcription purposes. Any names used in the recordings will be replaced with pseudonyms (made up name) in the written transcription. The audio recordings will be stored on an encrypted drive on the principal investigators computer. These recordings will be destroyed after three years' time.

Storage of Data: The tangible data of photographs, consent forms, and any printed transcription will be stored in a locked filing cabinet in the researcher's home office. The transcribed files and digital photographs will be encrypted and stored on the principal investigator's computer indefinitely. Only members of the research team will have access to these transcribed interviews, and that access will be limited to the files with real names replaced with pseudonyms.

Photography: As an integral part of this study, you will be responding to prompts through the artistic medium of photography. Photographs you take should not be pornographic and should not capture any illegal activities. You will receive a copy of each of the photographs that you capture, however, these photographs MAY NOT be published online (e.g. Facebook, Twitter, Tumblr, Pinterest, Instagram, etc.)

Potential Risks or Discomforts: Potential risks associated with participating in this study are minimal and will not exceed risks that are encountered in daily living. The only anticipated risk from participating in this study is that you may not feel comfortable answering some of the questions. You may choose not to answer any question that makes you uncomfortable and you may quit the study at any time.

Who to Contact Should You Experience Any Negative Effects from Participating in this Study

Should you experience any feelings of anxiety, distress, etc., there are counseling services available to you through the Ball State University Practicum Clinic in Muncie, IN. The fees for this clinic range from \$10 to \$1 per session and are your responsibility. The phone number for this clinic is 765-285-8047. If you are a student at Ball State University, please seek services at the University Counseling Center.

Benefits

One benefit you may gain from participating in this study may be a better understanding of how childhood cancer survivors experience life after survival.

Voluntary Participation: Your participation in this study is entirely voluntary. You are free to withdraw your permission to participate in this study at any time, for any reason, and without penalty or prejudice.

Compensation: As a thank you for your participation in this study you can choose to receive \$25 OR the investigator will make a donation of \$25 in your name to the children's hospital of your choosing after the end of the second meeting.

IRB Contact Information:

For one's rights as a research subject, you may contact the following: For questions about your rights as a research subject, please contact the Director, Office of Research Integrity, Ball State University, Muncie, IN 47306, 765-285-5070 or irb@bsu.edu

Study Title: A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood

Informed Consent

I, _____, agree to participate in the research project, *A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood*. The study has been explained to me and my questions have been answered to my satisfaction. I have read the description of this research study and give my consent to participate. I understand a copy of this consent form will be given to me for my records and for future reference.

To the best of my knowledge, I meet the inclusion criteria for participation in this study.

Participant Signature

Date of Consent

Exhibition Participation

If you are willing to participate and be a part of the exhibition of photographs collected during this study, please initial those items below for which you give permission. This exhibition will take place at the end of the researcher's defense of her dissertation. **Please initial one option below:**

_____ Yes, I would like to be a part of the photography exhibition of the photographs collected during this study **AND** would like to be present for the event.

_____ No, I would not like be a present at the photography exhibition of the photographs collected and you may only use my pseudonym with my pictures that are exhibited.

I understand my participation in this photography exhibition is completely voluntary and I can withdraw at any time without repercussion. By initialing above the "yes" option above, I expressly release Erin L. Sadler, her research team, Ball State, its agents, trustees, officers,

employees, licensees and assigns from and against any and all claims which I have or may have for invasion of privacy or any other cause of action arising out of or relating to my appearance in the photographs or presence at the photography exhibition.

Researcher Contact Information

Principal Investigator:

Erin L. Sadler, M.A., Doctoral Student
Counseling Psychology
Ball State University
Muncie, IN 47306
Telephone: (765) 285-8058
Email: elsadler@bsu.edu

Faculty Supervisor:

Dr. Donald R. Nicholas
Counseling Psychology
Ball State University
Muncie, IN 47306
Telephone: (765) 285-8058
Email: dnichola@bsu.edu

Appendix F

Demographic Data Form

Date: _____

Chosen Pseudonym: _____

Male/Female: _____

Age: _____

Self-described ethnicity: _____

Highest Completed Degree: _____

Type of Cancer Diagnosed: _____

Treatment Type: (circle) Chemotherapy Radiation therapy Surgery

Age at diagnosis: _____

Has there been any recurrence: Yes No

Years Since Last Treatment: _____

Relationship Status: (circle) Single Partnered Married Divorced

Widowed

Short Biography:

Appendix G

Media Release Form

Title of Study: A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood

Principal Investigator: Erin L. Sadler, M.A.

I have had an opportunity to read, review and ask questions about the above-named research project as part of the informed consent process. I understand that part of the research involves the use of various types of media (for example, audio recordings, digital and printed pictures, etc.). The following information was described to me by the researcher and in the informed consent form:

- The type or types of media to be used;
- How this media was to be used in the research project;
- Who would have access to it;
- What safeguards were to be used;
- What privacy and security precautions would be used
- How the media would be destroyed and when once the research was completed
- That I have the right to withdraw from the study at any time; and
- That I can receive a copy of both the informed consent form and this media release form for my records.

As such, I agree to allow the researcher to use the media described to me as part of the above named research project. This media will **be used only for the above-named project**, *unless* I give the researcher written permission (see page 2) for other possible uses.

For questions about your rights as a research subject, please contact the Director, Office of Research Integrity, Ball State University, Muncie, IN 47306, 765-285-5070 or irb@bsu.edu

Date

Signature

Printed Name

Contact for Follow-up Research and Non-research Related Media Uses

Title of Study: A Photovoice Exploration and Interpretive Phenomenological Analysis of the Experiences of Childhood Cancer Survivors

Principal Investigator: Erin L. Sadler, M.A.

There may be occasion for the researcher to contact you about follow-up or future *research* uses for the media collected.

****The media that was collected for the research purpose(s) described in the Informed Consent form will not be used or disclosed for any purpose(s) that you do not agree to below.****

If you are willing, however, to be contacted regarding other possible research-related uses or other *non-research*-related uses, please initial those items below for which you give permission. Only those items you initial will be used, all other uses will be prohibited. **Please initial any and all that apply:**

_____ I **give permission** to the research team to contact me about possible follow-up/future research uses of the media collected.

_____ I **give permission** to the research team to use my research-related media for any future research uses **without** the need to contact me.

_____ I **give permission** to the research team to contact me about possible follow-up non-research uses of the media collected.

_____ I **give permission** to the research team to use my research-related media for any future non-research uses **without** the need to contact me. **To that end, I understand and have also signed the attached agreement below.***

****Note: These authorizations are completely optional and voluntary. You do not need to agree to any of them in order to take part in the proposed research.****

Date

Signature

Printed Name

Appendix H

Photography Research Prompts

Please respond to some or all these questions by using photography.

- Some people have been negatively impacted by their illness. Some people have experienced personal growth as a result of their illness. Which have you experienced?
- Tell me your story with these photos.
- What is it like to be a childhood cancer survivor?
- How does the experience with cancer influence your life and hopes for the future?
- What would I like to tell others about surviving childhood cancer to bring awareness to this life experience?

Appendix I

Photography Instructions & Tips

Keep these tips handy as you do your Photovoice project. Refer to them often.

Photo-Taking Prompts

- Some people have been negatively impacted by their illness. Some people have experienced personal growth as a result of their illness. Which have you experienced?
 - Tell me your story with these photos.
 - What is it like to be a childhood cancer survivor?
 - How does the experience with cancer influence your life and hopes for the future?
 - What would I like to tell others about surviving childhood cancer to bring awareness to this life experience?
-

No experience needed! Owning a camera or having experience taking photographs is not necessary.

Photo quality is not important. Photovoice is not about the quality of your photographs. It is about taking pictures that mean something to you as childhood cancer survivor.

Keep a notebook. Write down ideas of photos in a notebook. Keep notes about why you took a picture.

Ask permission to take someone's photo. Always ask permission before you take someone's picture in a private space (house, inside vehicle, school, etc.)! If you think in advance you would like to take photographs of people in private spaces, please inform the principal investigator so she can obtain written consent and release BEFORE you take the photograph. Provide them with the flyer in your research participation packet and say something like "I'm working on a photography project to help people understand the experiences of childhood cancer survivors, would you mind being in one of the photos?" If they say no, that is okay! Thank them for their consideration and do not take their photograph. If they say yes, provide them with a Contact Information Form, have them fill it out, and then return it to the principal investigator and she will obtain consent and media release forms. If written consent and release is not obtained, this photograph of the person will not be able to be used in the study.

When permission is not necessary. In a public place like a park, you can take someone's photo without permission, especially if they are far away and can't be recognized in the picture.

Photo-Taking Tips

Tips for taking good photographs

- Try different angles
- Try different points of view
- Is your subject in the center of the photo?
- Does your subject fill the photo?
- Be creative! There are no rules per se as you are just asked to respond to the prompts in any way you like.

Tips for avoiding common mistakes

- Keep your finger away from the lens
- Don't cover the flash
- Stand about three to eight feet away from your subject
- Wind the film forward before you take another picture, if your camera does not do so automatically.
- To prevent blurry pictures, hold your elbows close to your sides, and hold your breath when you press the shutter (button).
- When taking photographs outside, keep the sunlight to your back or to the side.
- When taking photographs inside, use the flash.

Photovoice Ethics: Safety and Respect

With Photovoice, we are visual researchers as we take pictures of our lives with brain injury and talk about them with others.

As a visual researcher, you must keep certain guidelines in mind:

Stay safe! Make sure you are “safe” when you take the picture. For example: Stand on a solid surface. Look before you step into or cross a street. Be aware of things around you, like traffic.

Be respectful. If certain people don't want their photo taken, respect their feelings.

Be prepared. Be ready to explain about the project to family, friends, or strangers, if they ask what you are doing. A simple explanation is: “I am part of a Photovoice project investigating what it is like to be a childhood cancer survivor. We are taking photographs of our lives and talking about them with other people. Thank you for letting me take your picture.” Give them the Project Information Sheet in this packet if they would like additional information or would like to contact the researcher.

Respect the lives and safety of others. When you take photos for your project, think of people's safety first, and be respectful of their lives. For example:

- If your friend is diabetic and the doctor told them not to eat sweets, avoid taking a picture of them eating cake.
- If your friend doesn't have a driver's license, avoid taking a picture of them driving a car down the street.

Appendix J

Contact Information Form for Photographed Persons

First Name: _____

Last Name: _____

Street Address: _____

City: _____

State: _____

Zip Code: _____

Phone Number: _____

Email Address: _____

Best Time to Contact:

Morning

Afternoon

Evening

Preferred Method of Contact:

Mail

E-Mail

Telephone

Appendix K

Project Information Sheet for Potential Photographed Person

A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood

The purpose of this study is to understand the experiences of childhood cancer survivors into adulthood. A small group of childhood cancer survivors have decided to participate in this study. They will respond to prompts provided to them by the principal investigator through photographs. You are receiving this form because one of the study's participants would like to photograph you or your child as a response to one of the prompts. This methodology is called photovoice. Development of the photovoice methodology is credited to Caroline C. Wang and Mary Ann Burris. The three major aims of photovoice are: 1) to allow participants to document their lives on their own terms, 2) to raise critical consciousness among participants, and 3) to initiate positive change through reaching policy makers through the photographs and research project as a whole.

This research project is being undertaken by Erin L. Sadler, the study's principal investigator, a doctoral student at Ball State University. This study is Erin's dissertation, a requirement for her to obtain her doctoral degree from Ball State University in the Counseling Psychology program.

Each participant will take 27 photographs in response to a set of prompts. The principal investigator will engage participants in two interview/discussion sessions regarding the photographs.

Findings of this study will be presented in the principal investigator's dissertation and may also be presented in scholarly journal articles, conference presentations, and books. One goal of the photovoice methodology is to reach policy makers. As such, a public exhibition of the research and the photographs will be planned at the conclusion of the study.

If you have any questions about this project, you may contact the principal investigator via phone or email: Erin L. Sadler, (765) 285-8058 or elsadler@bsu.edu

You may also direct questions to: Office of Research Integrity, Ball State University, Muncie, IN 47306, (765) 285-5070, irb@bsu.edu

Appendix L

Photo Consent Form for Photographed Adult**Study Title**

A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood

Inclusion/Exclusion Criteria

Participants involved in this study have been asked to respond to prompts through photographs. You are receiving this form because one of the study's participants would like to photograph you as a response to one of the prompts.

Data Confidentiality or Anonymity

All photographs will be maintained as confidential and no identifying information such as names will appear in any publication or presentation of the data. You may be identifiable through the photographs, however. Photographs of you will not be taken, presented, exhibited, or otherwise published without your consent and release.

Storage of Data

Tangible photographs will be stored in a locked filing cabinet in the researcher's office indefinitely. Electronic photographs will be stored on the researcher's password-protected laptop indefinitely. Participants will be given one copy of all photographs they take as they are requested. Aside from the photographer/participants, only members of the research team will have access to the photographs for the purposes of analysis.

Voluntary Participation

Allowing yourself to be photographed for this study is completely voluntary. Please feel free to ask any questions of the researcher before signing this photo consent and release form and at any time during the study.

Researcher Contact Information

For additional information about this study, you may contact the principal investigator: Erin Sadler, (765) 285-8058 or elsadler@bsu.edu. You may also contact the principal investigator's supervisor, Dr. Donald Nicholas, at (765) 285-8058, dnichola@bsu.edu.

IRB Contact Information

You may also direct questions to: Director, Office of Research Integrity, Ball State University, Muncie, IN 47306, 765-285-5070 or irb@bsu.edu

Photo Consent

I, _____, give permission to be photographed by participants of this research project entitled, *A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood*. I have had the study explained to me and my

questions have been answered to my satisfaction. I have read the description of this project and give permission for myself to be photographed and for the photograph to be presented, published, and exhibited as a part of this research project. I understand that I will receive a copy of this informed consent form and photo release form to keep for future reference.

Printed Name

Signature

Date

Name of Photographer

For participant/photographer's use only:
Photograph number(s) in which this individual appears:

Appendix M

Parent/Guardian Photo Consent Form for Photographed Child/Minor**Study Title**

A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood

Inclusion/Exclusion Criteria

Participants involved in this study have been asked to respond to prompts through photographs. You are receiving this form because one of the study's participants would like to photograph your child as a response to one of the prompts.

Data Confidentiality or Anonymity

All photographs will be maintained as confidential and no identifying information such as names will appear in any publication or presentation of the data. Your child may be identifiable through the photographs, however.

Storage of Data

Tangible photographs will be stored in a locked filing cabinet in the researcher's office indefinitely. Electronic photographs will be stored on the researcher's password-protected laptop indefinitely. Participants will be given one copy of all photographs they take as they are requested. Aside from the photographer/participants, only members of the research team will have access to the photographs for the purposes of analysis.

Voluntary Participation

Allowing your child to be photographed for this study is completely voluntary. Please feel free to ask any questions of the researcher before signing this photo consent and release form and at any time during the study.

Researcher Contact Information

For additional information about this study, you may contact the principal investigator: Erin Sadler, (765) 285-8058 or elsadler@bsu.edu. You may also contact the principal investigator's supervisor, Dr. Donald Nicholas, at (765) 285-8058 or dnichola@bsu.edu.

IRB Contact Information

You may also direct questions to: Director, Office of Research Integrity, Ball State University, Muncie, IN 47306, 765-285-5070 or irb@bsu.edu

Photo Consent and Media Release

I, _____, give permission for my child to be photographed by participants of this research project entitled, *A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood*. I have had the study explained to me

and my questions have been answered to my satisfaction. I have read the description of this project and give permission for my child to be photographed and for the photograph to be presented, published, and exhibited as a part of this research project. I understand that I will receive a copy of this informed consent form and media release form to keep for future reference.

Printed Name

Signature

Date

Name of Photographer

For participant/photographer's use only:

Photograph number(s) in which this individual appears:

Appendix N

A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood

Assent Form

My name is Erin Sadler. I am trying to learn about how people adjust after surviving childhood cancer because we do not know a lot about how it can change people after the cancer goes away. If you would like, you can a part of my study.

If you decide you want to be in my study, you will let one of the people who agreed to participate in my study take your picture.

Nothing bad will happen to you if you let the participant take your photograph. You would be helping him or her explain and talk about his or her life. It could help other people understand childhood cancer survivors' lives and how to make them better.

Other people will not know if you are in my study, but some people might see who you are in the picture. When I tell other people about my research, I will not use your name, so no one can tell whom I am talking about. Your picture might be in an article or story about childhood cancer survivors, but no one will know your name.

Your parents or guardian have to say it's OK for you to be in the study. After they decide, you get to choose if you want to do it too. If you don't want to be in the study, no one will be mad at you. If you want to be in the study now and change your mind later, that's OK. You can stop at any time.

My telephone number is 765-285-8058. You can call me if you have questions about the study or if you decide you don't want to be in the study any more.

I will give you a copy of this form in case you want to ask questions later.

Agreement

I have decided to be in the study even though I know that I don't have to do it. Erin has answered all my questions.

Signature of Study Participant

Date

Signature of Researcher

Date

Appendix O

Semi-Structured Interview Questions

- What does the photograph mean to you?
- Tell me the story of this photograph.
- What does this mean to you?
- What is it like to be a survivor of childhood cancer?
- How does this photograph represent what it is like to be a survivor of childhood cancer?
- What have been some significant highs and lows after having childhood cancer?
- What are the most challenging parts about being a childhood cancer survivor?
- What are some things you have learned from your illness?
- What kind of meaning have you made of your illness?

Appendix P

Process & Termination Questions

- What was it like to be a part of this project?
- How did you decide what to photograph?
- What was it like for you to talk about your photographs?
- Was this project difficult for you? Why/Why not?
- Was this project enjoyable for you? Why/Why not?
- What did you gain or learn from this experience, if anything?
- Do you plan to be involved in the photo exhibition?

Appendix Q

IRB Approval Letter



Office of Research Integrity
Institutional Review Board (IRB)
2000 University Avenue
Muncie, IN 47306-0155
Phone: 765-285-5070

DATE: October 9, 2014

TO: Erin Sadler, M.A.

FROM: Ball State University IRB

RE: IRB protocol # 605830-2

TITLE: A Photovoice Exploration and Interpretive Phenomenological Analysis of Childhood Cancer Survivorship into Adulthood

SUBMISSION TYPE: Revision

ACTION: APPROVED

DECISION DATE: October 9, 2014

EXPIRATION DATE: October 8, 2015

REVIEW TYPE: **Expedited:** This protocol had been determined by the board to meet the definition of minimal risk.

The Institutional Review Board has approved your Revision for the above protocol, effective October 9, 2014 through October 8, 2015. All research under this protocol must be conducted in accordance with the approved submission and in accordance with the principles of the Belmont Report.

Review Type:

	Category 1: Clinical studies of drugs and medical devices
	Category 2: Collection of blood samples by Finger stick, Heel stick, Ear stick, or Venipuncture
	Category 3: Prospective collection of biological specimens for research purposes by noninvasive means
X	Category 4: Collection of data through Non-Invasive Procedures Routinely Employed in Clinical Practice, excluding procedures involving Material (Data, Documents, Records, or Specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis)
	Category 5: Research involving materials that have been collected or will be collected solely for non-research purposes.
X	Category 6: Collection of Data from Voice, Video, Digital, or Image Recordings Made for Research Purposes

	Category 7: Research on Individual or Group Characteristics or Behavior or Research Employing Survey, Interview Oral History, Focus Group, Program Evaluation, Human Factors, Evaluation, or Quality Assurance Methodologies
	Category 8: Continuing review of research previously approved by the convened IRB
	Category 9: Continuing review of research, not conducted under an investigational new drug application or investigational device exemption where categories 2-8 do not apply but the IRB has determined and documented at a convened meeting that the research involves no greater than minimal risk and not additional risks have been identified.

Editorial Notes:

1. Approved

As a reminder, it is the responsibility of the P.I. and/or faculty sponsor to inform the IRB in a timely manner:

- when the project is completed,
- if the project is to be continued beyond the approved end date,
- if the project is to be modified,
- if the project encounters problems, or
- if the project is discontinued.

Any of the above notifications must be addressed in writing and submitted electronically to the IRB (<http://www.bsu.edu/irb>). Please reference the IRB protocol number given above in any communication to the IRB regarding this project. Be sure to allow sufficient time for review and approval of requests for modification or continuation. If you have questions, please contact John Mulcahy at (765) 285-5106 or jmulcahy@bsu.edu.

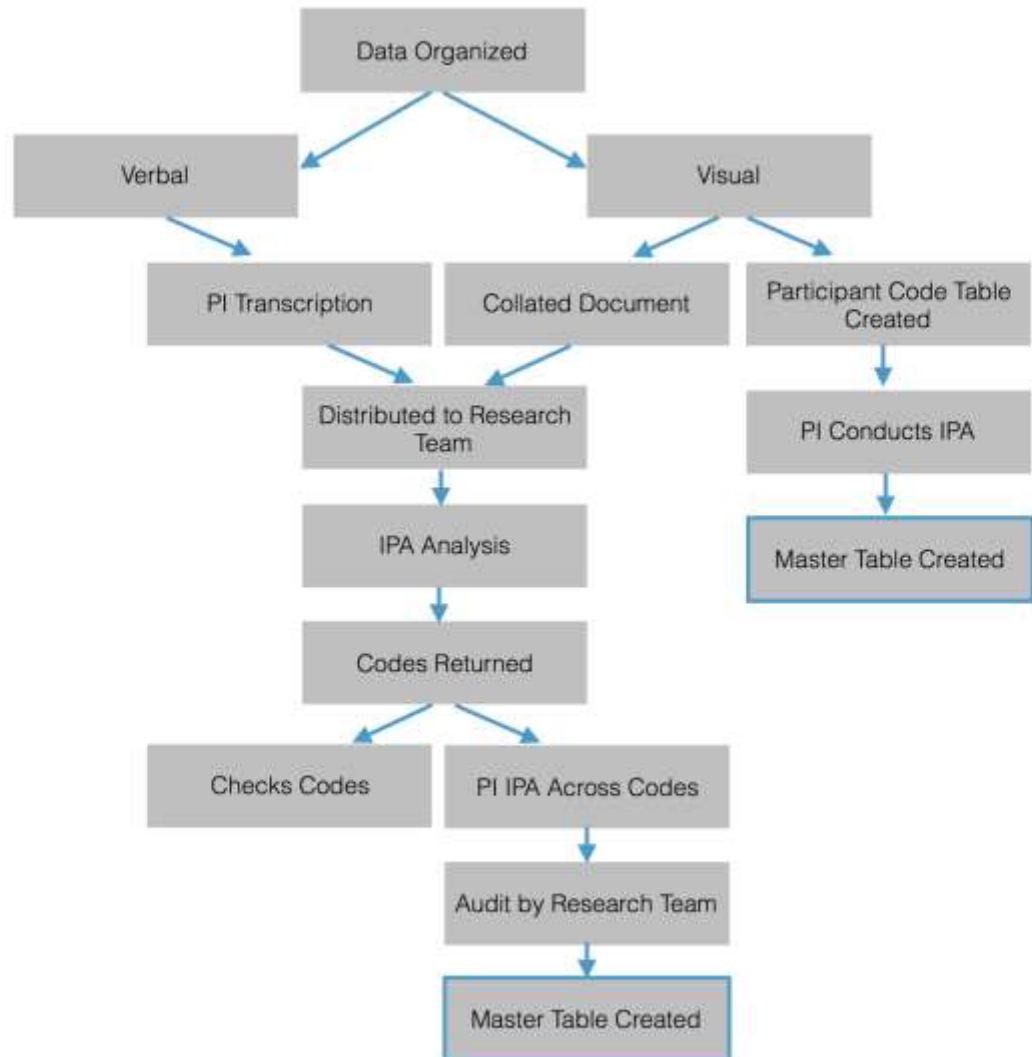
In the case of an adverse event and/or unanticipated problem, you will need to submit written documentation of the event to IRBNet under this protocol number and you will need to directly notify the Office of Research Integrity (<http://www.bsu.edu/irb>) **within 5 business days**. If you have questions, please contact (ORI Staff).

Please note that all research records must be retained for a minimum of three years after the completion of the project or as required under Federal and/or State regulations (ex. HIPAA, FERPA, etc.). Additional requirements may apply.

Bryan Byers, PhD/Chair
Institutional Review Board

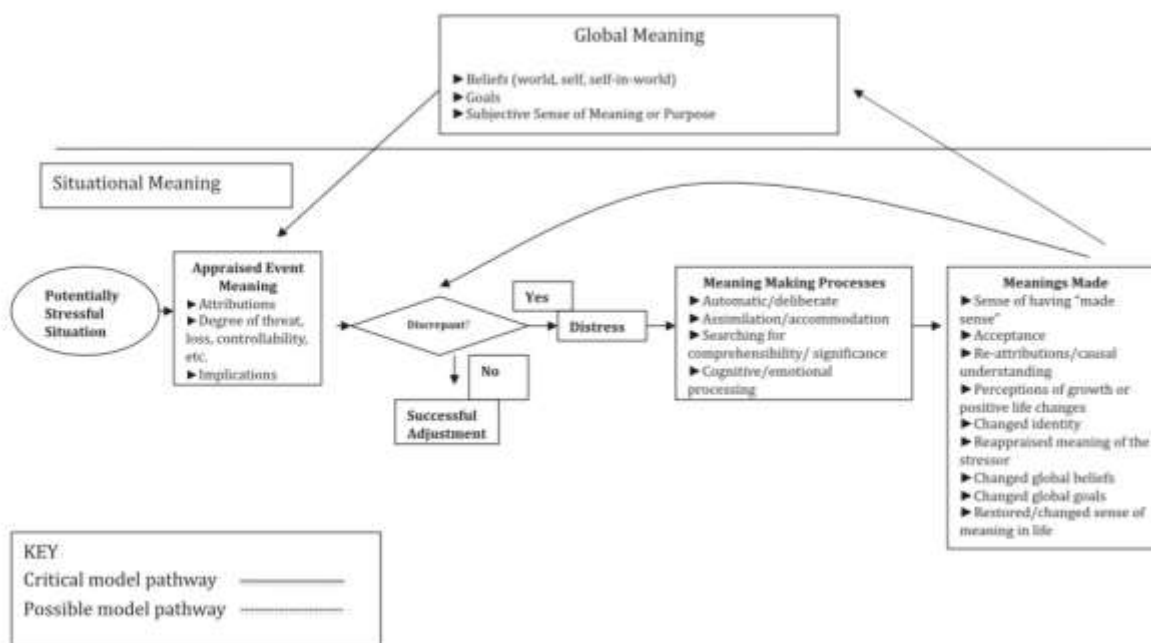
Christopher Mangelli, JD, MS, MEd, CIP/Director
Office of Research Integrity

Appendix R
Data Analysis Process



Appendix S

Park's (2010) Meaning-Making Model



Appendix T

Tedeschi and Calhoun's (2004) Model of Posttraumatic Growth

